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ABSTRACT

This bibliography lists and abstracts approximately 550 selected resources (books, monographs, and unpublished but publicly available documents) on community integration for people with developmental and other disabilities. Emphasis is on inclusion for people with severe disabilities and selection was based on the degree to which a resource reflected established principles of community integration. Documents were originally published from approximately 1980 through 1998. References are grouped into the following topic areas: (1) philosophy and perspectives on community integration; (2) administrative issues; (3) services and supports for integration; (4) education in the regular classroom; (5) integrated employment, including services and supports; (6) recreation and leisure opportunities; (7) beyond paid services and supports; (8) personal narratives; (9) women with disabilities; (10) sexuality; (11) abuse and violence; (12) multiculturalism and diversity; and (13) disability studies. Also included are a list of publishers' addresses, a list of organizations concerned with community integration, and a title index. (DB)

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ED 420 946

ANNOTATED BIBLIOGRAPHY ON COMMUNITY INTEGRATION THIRD EDITION

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INTRODUCTION

This Annotated Bibliography on Community Integration, Third Edition lists many of the best available resources on community integration for people with developmental and other disabilities. It is meant to be a resource for people with disabilities, parents and family members, advocates and friends, direct service providers, administrators, and policy makers who are interested in promoting the participation of people with developmental disabilities in all aspects of community life. It presents resources applicable to many disability groups and represents an extensive revision and updating of the Annotated Bibliography on Community Integration prepared by the Center on Human Policy's Community Integration Project in 1987 and revised in 1990.

Selection Process

Materials for both editions were initially identified by computerized searches of the ERIC (Educational Resource Information Center), NIMH (National Institute for Mental Health), and MEDLARS (Medical Literature Analysis and Retrieval System) databases and a review of (a) bibliographies published by the American Association on Mental Retardation, ERIC, NARIC (National Rehabilitation Information Center), the Beach Center, the Institute on Community Integration (University of Minnesota), the University Affiliated Program (UAP) on Developmental Disabilities (University of Illinois at Chicago), the Institute on Disability (University of New Hampshire), and other centers engaged in work in the area of community integration; (b) publication lists of major publishers and research centers; and (c) the nominations of the staff and associates of the National Resource Center on Community Integration at the Center on Human Policy. Materials culled from this first step were then individually reviewed for inclusion based on the criteria outlined below.

Selection Criteria

The materials identified for this bibliography clearly focus on inclusion for people with severe disabilities. We evaluated each resource for the degree to which it reflected the principles of the Center on Human Policy's National Resource Center on Community Integration:

1. All people with developmental disabilities, including those with the most severe disabilities, belong in the community.
2. Agencies and programs should provide the services and supports people with developmental disabilities need to participate in typical neighborhoods, work settings, and community environments.
3. Agencies and programs should support children to live with families and adults to live in typical homes in the community.

4. Agencies and programs should foster the development of relationships between people with developmental disabilities and other community members.
5. Programs and services provided to people with developmental disabilities should be non-aversive, oriented toward the development of practical life skills, and respectful of personal choices.
6. Parents and people with disabilities themselves should be involved in the design, operation, and monitoring of services.

For this revision, we included books, monographs, and unpublished but publicly available documents. (Relevant journal articles are compiled separately, in Community Integration Abstracts, published by the Center on Human Policy.) For the most part, we eliminated materials that reflected a facility-based point of view, even those that use language implying a community integration philosophy. We identified many materials that promote a "support" rather than a "program" paradigm; that is, they discuss ways of supporting individuals to express and carry out their own choices and preferences for where and with whom they will work, learn, play, and live. We feel that the materials included here reflect a coherent vision of the opportunities people with severe disabilities should have today. We also want to note that the field continues to change, as do the visions of people with disabilities and their families. We hope that some of the resources included here reflect the visions of tomorrow.

Organization of This Bibliography

Much of this bibliography is divided into sections that reflect different areas in the lives of people with disabilities. We hope that readers will realize that no person's life can be divided neatly into domains, and that no section of this bibliography can stand alone. Within each section, the materials are organized alphabetically by author. There are two indices in the back to assist readers to find materials by author and by title.

Acknowledgments

The editors would like to thank all of the contributors to this edition, including Steve Taylor, Bonnie Shoultz, Perri Harris, Julia Searl, Susan O'Connor and Marj Olney. Special thanks go to Debbie Simms and to Rachael Zubal for putting the document together, organizing all the pieces into a workable whole. Appreciation is also extended to James Knoll, who edited the first edition in 1987 and to Bonnie Shoultz, who edited the second edition.

This bibliography was prepared with support from the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), awarded to the Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University under Cooperative Agreement No. H133D50037. The opinions expressed herein are those solely of the authors and do not necessarily reflect the position or the policy of the U.S. Department of Education and no official endorsement should be inferred.

PHILOSOPHY AND PERSPECTIVES ON COMMUNITY INTEGRATION

The materials reviewed in this section are intended to give the reader an overview of the historical and ideological perspectives which inform the community integration movement. For that reason, some of these materials may now seem outdated or overly broad, while others are very current. They are presented here because the complex nature of the forces encountered by people with disabilities, parents, and practitioners require a good understanding of the basis for community services and supports and a strong commitment to the principle that the community should include everyone. For more on the perspectives of people with disabilities and family members, please see the "self-advocacy," "families," and "disability studies" sections of this bibliography.

TITLE: Communication unbound: How facilitated communication is challenging traditional views of autism and ability/disability

AUTHOR: Biklen, D.

PUBLICATION INFORMATION: 1993

New York: Teachers College Press

In 1989, Biklen spent a month in Melborne, Australia at Rosemary Crossley's DEAL Center for augmented communication carrying out a qualitative study of students with autism who used facilitated communication (FC). Returning to New York, Biklen then proceeded to publish the findings of this study and to introduce FC into his local schools. Communication unbound chronicles, through the richness of examples, the stories of what he learned in Australia and attempts to bring this knowledge back to the US. Topics covered include: toward an understanding of FC, introduction of FC here, "I'm not autistic on the typewriter," breakthroughs and the difficulties of change, validation controversies, rethinking disability and communication, and ending the ability/disability dichotomy.

TITLE: Contested words, contested science: Unraveling the facilitated communication controversy

AUTHORS: Biklen, D., & Cardinal, D.

PUBLICATION INFORMATION: 1997

New York: Teachers College Press.

Since the formal introduction of FC into the United States, considerable controversy has surrounded the use of FC for students with labels of autism. Is FC real, who has authorship over that which is communicated through typing, why were earlier studies not able to validate FC, what is communication, and is FC 'real communication?' This book carries out an in-depth consideration of the controversy that has surrounded FC. The authors look at possible reasons for which past studies continually gave non-validating results and then examine the results of new studies which show that FC is indeed communication. Specifically, they look at using portfolios to confirm authorship, factors that affect performance with FC, multiple meanings of independence, and the concept of presuming competence.

TITLE: The community imperative revisited

AUTHORS: Biklen, D., & Knoll, J.

PUBLICATION INFORMATION: 1987

In J. A. Mulick & R. F. Antonak (Eds.), Transitions in mental retardation, Vol. III: The community imperative re-examined (pp. 1-27). Norwood, NJ: Ablex.

Ablex
355 Chestnut Street
Norwood, NJ 07648

In 1979, the Center on Human Policy issued The Community Imperative Declaration, which asserts that "All people, regardless of the severity of their disabilities, are entitled to community living." This statement and an accompanying paper became a rallying point for people everywhere who believed in community living for all. This chapter "revisits" the statement and its aftermath, systematically refuting eight major arguments which oppose this position and citing the experiences of a number of formerly institutionalized people. The chapter provides a comprehensive review of the literature on this topic and highlights a number of obstacles which continue to hinder realization of the Community Imperative's goal.

TITLE: The family papers: A return to purgatory

AUTHORS: Blatt, B., Ozolins, A., & McNally, J.

PUBLICATION INFORMATION: 1979

New York: Longman

This valuable resource is currently out-of-print. It should be available at any library with a solid collection in the area of special education.

A slide show based on the book, The Family Album, is available through the Human Policy Press, P.O. Box 127, University Station, Syracuse, NY 13210.

In 1966, Burton Blatt and Fred Kaplan, the former a respected professional in the field of mental retardation and the latter a photographer, shocked America's conscience with the publication of Christmas in Purgatory, a photographic exposé of conditions in institutions for people with mental retardation. Ten years later, Blatt, this time with Andrejs Ozolins and Joe McNally, returned to these institutions to document the changes and reforms that had occurred since the earlier expose. The findings are contained in The family papers. Filled with photographs of institutions and alternative settings, this book at once documents improved conditions at institutions and captures the more subtle forms of dehumanization which occur there today. As the authors conclude, "As you will see, everything has changed during the last decade. As you will see, nothing has changed." The book presents a compelling argument in favor of community living. Policymakers, parents, and professionals new to the field will find this book especially informative.

TITLE: Evolution of a new service paradigm

AUTHOR: Bradley, V. J.

PUBLICATION INFORMATION: 1994

In V.J. Bradley, J.W. Ashbaugh, & B.C. Blaney (Eds.), Creating individual supports for people with developmental disabilities: A mandate for change at many levels (pp. 11-32). Baltimore: Paul H. Brookes Publishing Co.

This chapter "addresses the theoretical variations that have precipitated change from the 1960s to the 1990s..." It begins with a section discussing the background "hallmarks of change" such as the evolution of the normalization principle and the change in paradigms from a medical model to a developmental model to a community membership model. Subsequent sections discuss the era of institutional reform, retrenchment and a realistic reappraisal. Next, the community membership paradigm is delineated. The keystones of this paradigm are discussed, that is: a commitment to community and families, human relationships, functional programming and individualization, and flexibility and individualized supports. Implications for the field are presented, including implications for service providers, for staff, and for the service system.

TITLE: Criterion of ultimate functioning and public school services for the severely handicapped student

AUTHORS: Brown, L., Nietupski, J., & Hamre-Nietupski, S.

PUBLICATION INFORMATION: 1976

In M. A. Thomas (Ed.), Hey, don't forget about me: Education's investment in the severely, profoundly, and multiply handicapped (pp. 2-15). Reston, VA: Council for Exceptional Children.

This valuable resource is currently out-of-print. It should be available at any library with a solid collection in the area of special education.

The case is made in this chapter that programs for individuals with severe disabilities have been oriented toward preparing these people to function in segregated environments. The authors propose a redirection of practice in services to severely handicapped persons toward what they call the Criterion of Ultimate Functioning--"the ever changing, expanding, localized, and personalized cluster of factors that each person must possess in order to function as productively and independently as possible in socially, vocationally, and domestically integrated adult community environments." Some of the factors suggested to facilitate this orientation are 1) integration into heterogeneous community environments; 2) a system of services for persons with severe disabilities which are longitudinal, comprehensive, and coordinated; and 3) the use of instructional approaches that are specifically geared toward teaching needed skills in natural environments.

TITLE: Site visit reports

AUTHOR: Center on Human Policy

PUBLICATION INFORMATION: 1985-1998

Center on Human Policy
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280

Beginning in 1985, Center on Human Policy staff have conducted site visits to agencies nominated as demonstrating promising practices in community integration. This series of reports includes views of agencies engaged in supporting adults to live in the community, family support, citizen advocacy, employment, integrated recreation

and leisure opportunities, and other types of support of people with severe disabilities. To obtain a listing and description of each report (a number of which are annotated in other sections), write to the address above.

NOTE: Paul H. Brookes Publishing Co. has published two books that contain a number of these case studies: Life in the community: Case studies of organizations supporting people with disabilities in the community (1991) and Housing, support, and community: Choices and strategies for adults with disabilities (1993). They can be obtained by contacting: Paul H. Brookes Publishing Co., P.O. Box 10624, Baltimore, MD 21285-0624; (410) 337-9580.

TITLE: Normalization, social integration, and community services

AUTHORS: Flynn, R. J., & Nitsch, K. E. (Eds.)

PUBLICATION INFORMATION: 1980

Pro ED
5341 Industrial Oak Boulevard
Austin, TX 78735

This is an edited book that provides a comprehensive review of the principle of normalization. The book is divided into three parts. Part I, "The Normalization Principle: Systematic Statements and Clarifications," includes articles authored by Wolf Wolfensberger, Bengt Nirje, and Neils E. Bank-Mikkelsen which provide an update on the meaning of normalization and address common misconceptions of the principle. Part II, "The Normalization Principle: Implications for Legislating, Implementing, and Evaluating Community Services," contains ten separate articles which deal with legal issues (especially, the implications of the Pennhurst case), special education (a classic article on least restrictive educational environments written by Lou Brown and others), early childhood education, the research on community residential settings, vocational services, regional planning for "communitization," a "supermarket of services" for elderly adults, and program evaluation based on normalization. Part III of the book contains a conclusion by the editors and a comprehensive bibliography of normalization references. Policymakers, planners, and administrators will find this book most useful.

TITLE: Supported community life and mediating structures: Joining theory to practice in disability policy reform

AUTHORS: Hibbard, M., Ferguson, P., Leined, J., & Schaff, S.

PUBLICATION INFORMATION: 1989

In P. Ferguson & D. Olson (Eds.), Supported community life: Community policy to practice in disability research. Portland: Specialized Training Program, University of Oregon.

Specialized Training Program
University of Oregon
College of Education
Eugene, OR 97403

This excellent essay explores basic contradictions in traditional social welfare policy, such as its basis in a belief in individual rights and entitlements as opposed to the large-scale institutions and systems that are developed to carry out social policy, and the loss of community and structures that might mediate the influence of "megastructures" on individual lives. It goes on to point out that while these contradictions have also shaped disability policy, the past few years have seen a new concept in disability policy, that of "supported community life," that can be explicated so as to be seen as a mediating structure. The authors point out that "What is new in the notion of Supported Community Life is the guiding commitment to participation and affiliation rather than control and remediation." The essay goes on to discuss services relevant to several life domains that are now framed as supports (supported employment, supported living, etc.) rather than just as programs or services. Finally, it illustrates the ideas being proposed by focusing in on family support services that illustrate the concept of support and that place control with the family, examining the supportive qualities of several programs. This chapter is worth reading for its excellent syntheses of trends in disability policy.

TITLE: Changing patterns in residential services for the mentally retarded

AUTHORS: Kugel, R. B., & Wolfensberger, W. (Eds.)

PUBLICATION INFORMATION: 1979

President's Committee on Mental Retardation
U.S. Department of Health and Human Services
Office of Human Development Services
Washington, DC 20201

Originally published in 1969, it now includes some new and some revised chapters.

This report, published by the President's Committee on Mental Retardation, is perhaps the single most influential document in the change from segregation and isolation toward normalization and community integration of people with disabilities.

The report outlines the status of residential facilities in the late 1960s and describes them "...as a disgrace to the nation" (p. 1), and delineates alternative ways of providing services. The contributors to this volume include several outstanding U.S. leaders in the field of mental retardation such as Burton Blatt, Gunnar Dybwad, Robert Kugel, Seymour Sarason, and Wolf Wolfensberger, as well as a number of European leaders, among them N.E. Bank-Mikkelsen (Denmark), Karl Grunewald (Sweden), Bengt Nirje (Sweden), David Norris (England), and Jack Tizard (England).

The report represented more than just another condemnation of the status of institutional programs in the U.S. in the 1960s. It also provided a thorough examination of the present service system, outlined new ways of providing services, and courses for action. Maybe most importantly, it was this report that brought the normalization principle to the nation's attention in a chapter written by Bengt Nirje where he outlines the theoretical construct of normalization which already at that time underlined much of the Scandinavian legal and service structure in mental retardation. The editors of the volume note that they "...view the normalization principle as perhaps the single most important concept that has emerged in this compendium" (p. 10). Although many of the ideas presented in this report are outdated by now, this historical and classic document was the turning point in the history of services for people with disabilities in the U.S.

TITLE: An overview of the community living concept

AUTHORS: Lakin, K. C., Hayden, M. F., & Abery, B. H.

PUBLICATION INFORMATION: 1994

In M. F. Hayden & B. H. Abery (Eds.), Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities (p. 3-22). Baltimore: Paul H. Brookes Publishing Co.

This chapter presents a framework developed by the Rehabilitation Research and Training Center on Residential Services and Community Living (a collaborative program involving the Institute on Community Integration (UAP) at the University of Minnesota, the Center on Human Policy at Syracuse University, and the University Affiliated Program on Developmental Disabilities at the University of Illinois at Chicago) to describe the meaning of community living. Within the RRTC, community living is viewed as the "effort to improve one's quality of life within collectives called communities." This chapter identifies and discusses six aspects of quality of life: presence in the community; health, safety, and basic comfort; opportunity for personal growth and development; social relationships; valued community participation; and personal self-determination.

TITLE: The careless society: Community and its counterfeits

AUTHOR: McKnight, J.

PUBLICATION INFORMATION: 1995

Basic Books
10 East 53rd Street
New York, NY 10022

This book is a compilation of the author's writings between 1974 and 1994. The chapters document the effect of the service system invasion on various aspects of society, attempting to describe both the futility of the counterfeit and the nature of the authentic care it replaced. The discussions point out that our problem is not ineffective service-producing institutions. In fact, our institutions are too powerful, authoritative, and strong. Our problem is weak communities, made ever more impotent by our strong service systems. Sections of the book cover various topics including: professionalism, medicine, human service systems, the criminal justice system, community, and Christian service.

TITLE: Perspectives on disability

AUTHOR: Nagler, M. (Ed.)

PUBLICATION INFORMATION: 1990

Health Markets Research
851 Moana Court
Palo Alto, CA 94306

In the introduction, the editor states, "The purpose of this text is to identify the significant and paramount concerns of the disabled community and to illuminate the obstacles which are often imposed on this minority. Further, it is the intention of this book to remedy the lack of comprehensive information about the disabled and to present some of the conflicting perspectives which surround many disabled issues." The book is divided into ten sections with chapters presenting the perspectives of people with and without disabilities. The sections include: what it means to be disabled, societal attitudes about disability, social encounters, family experiences, sexuality and disability, educational opportunities and barriers, employment and disabled workers, legal issues, medical concerns, and what it means to be different: perspectives of the disabled. An appendix contains a bibliography of American and Canadian disability organizations.

TITLE: What can we count on to make and keep people safe? Perspectives on creating effective safeguards for people with developmental disabilities

AUTHORS: O'Brien, J., O'Brien, C. L., & Schwartz, D. B. (Eds.)

PUBLICATION INFORMATION: 1990

Lithonia, GA: Responsive Systems Associates.
(Available through the Center on Human Policy)

This excellent and readable monograph is a report on a discussion between participants in a 1989 annual retreat of the Pennsylvania Developmental Disabilities Planning Council. It includes summaries of parts of the discussion and selections from background papers used by participants, and deals with questions that encompass, but are much broader than, quality assurance. The editors see the question in the title as one that "frames an important perspective on the continuing work of building communities that offer people with developmental disabilities full and dignified lives." The paper recognizes the vulnerability of people who need long-term assistance to realize their citizenship and community membership, and deals with the insufficiency of currently favored mechanisms for ensuring safety. The discussion looks at various types of advocacy, at lifesharing and other personal commitments, and at support for what families, friends, and service workers do. It also discusses strategies and options for action to increase people's safety.

TITLE: The national reform agenda and people with mental retardation: Putting people first

AUTHOR: President's Committee on Mental Retardation

PUBLICATION INFORMATION: 1994

U.S. Dept. of Health and Human Services
Wilbur J. Cohen Building, Room 5325
330 Independence Ave., S.W.
Washington, DC 20201

This monograph contains the proceedings of the 1994 meeting of the President's Committee on Mental Retardation. Included are perspectives of self-advocates, parents, administrators, and others. Additional topics covered include legislative concerns, school to work, older citizens with developmental disabilities, and cultural diversity and citizens with disabilities. The monograph also contains reports and

recommendations from PCMR workgroups on: health care reform, welfare reform, long-term care reform, housing reform, education reform, and employment/financing reform.

TITLE: The Willowbrook wars: A decade of struggle for social justice

AUTHORS: Rothman, D. J., & Rothman, S. M.

PUBLICATION INFORMATION: 1984

New York: Harper and Row.

Though this book is out-of-print, it should be available at university and municipal libraries or through interlibrary loan services.

This book traces the history of reforms and litigation at the infamous Willowbrook State School in Staten Island, New York from 1972 to 1983. While the book focuses on the specific experience at Willowbrook, it has general relevance to the issues of institutional reform, the impact of courts on service systems, parent involvement, deinstitutionalization, and community-based services for people with severe disabilities.

Practically everyone interested in people with severe developmental disabilities will find The Willowbrook wars interesting and useful. Parents will identify with the heart-wrenching experiences and dilemmas of parents of people at Willowbrook. Policy makers and planners will find important lessons about the complexity of reform, systems change, and developing community services. Attorneys and advocates will gain additional insight into the impact of their activities. Service providers will learn about approaches for gaining community acceptance, designing humane and effective programs, planning strategies, the importance of independent monitoring, and current controversies over issues like the size of community living arrangements and community fears of "Hepatitis B carriers." Written in clear language and an engaging style, The Willowbrook wars is "must" reading for people interested in the community integration movement.

TITLE: Crisis in the community

AUTHOR: Smull, M. W.

PUBLICATION INFORMATION: 1989

National Association of State Directors of
Developmental Disabilities Services, Inc. (NASDDDS)
113 Oronoco Street
Alexandria, Virginia 22314

In this paper, Smull provides strong evidence that community services are in crisis--that understaffing and underfinancing, combined with rigid and inefficient models of service, are having an increasingly adverse effect on quality of care. He proposes a reconceptualization of services, a move from a "program paradigm" to a "support paradigm," as a way of bringing resolution to the crisis. He proposes changes in the way we think about people and services, changes in how our programs are staffed and organized, and changes in funding and regulation.

The support paradigm, Smull argues, sees people with developmental disabilities as having choices of all sorts, and as getting the support they need to realize their choices. It sees people as participants in community life, with support, taking advantage of opportunities rather than doing what they are told. The support paradigm will mean a "messier" service system, one that encourages the use of the resources of the person, the family, and the community while it uses staff in radically different patterns to carry out the wishes of the people they work for. This paper is worth sending for--Smull expertly delineates the problems with the current community service system and proposes real ways of thinking about solutions to the crisis.

TITLE: Community integration for people with severe disabilities

AUTHORS: Taylor, S. J., Biklen, D., & Knoll, J. (Eds.)

PUBLICATION INFORMATION: 1987

New York: Teachers College Press.

This volume begins with a set of principles for community integration. The remainder of the book is divided into three parts. Part I, entitled "Policy, Principles, and Practices," contains three chapters that address broad issues related to community integration, including prejudice and problems with the continuum. Part II, entitled "Leadership," offers different perspectives on designing and operating services for people with developmental disabilities. These authors argue that it is leadership and commitment, not bureaucratic or technical expertise, that make programs effective and responsive. Part III, "With the People," contains four chapters that look at different slices of community life. The concluding chapter reflects on key themes introduced in the book, presents some lessons learned, and looks at future issues in community integration.

TITLE: The disabled in America: History, policy and trends

AUTHORS: Taylor, S. J., & Searl, S. J., Jr.

PUBLICATION INFORMATION: 1987

In P. Knoblock (Ed.), Understanding exceptional children and youth (pp. 5-64). Boston: Little, Brown.

Little, Brown
1271 Avenue of the Americas
New York, NY 10020

This chapter provides a detailed review of the history and trends in disability policy in the U.S. The authors present an extensive discussion on the history of institutions, including origins, as well as the era of institutional expansion and accompanying trends (including eugenics, sterilization, restrictive immigration). They also describe the emergence of special education in the public schools. In a section entitled, "A Time of Change," the authors describe developments in the 1950s and 1960s, including the parent/consumer movement, exposes, and litigation. There is extensive discussion on major legal cases and the federal response, including the ICF/MR program, Section 504 of the Rehabilitation Act, and P.L. 94-142. The next section describes serious challenges, that occurred in the late 1970s and 1980s, to progress that had been made, with backlash and debate among parents, professionals, politicians, and members of the general public. The final section raises current and future issues for the 1980s and beyond.

TITLE: Inventing the feeble mind: A history of mental retardation in the United States

AUTHOR: Trent, J. W., Jr.

PUBLICATION INFORMATION: 1994

University of California Press
2120 Berkeley Way
Berkeley, CA 94720

In this book, Trent traces the history of mental retardation in the U.S. from the early 1800s onward. He uses public documents, private letters, investigative reports, and rare photographs to explore our changing perceptions of mental retardation. He contends that the economic vulnerability of people labeled mentally retarded (and their

families), more than the claims made for their intellectual or social limitations, has determined their institutional treatment. At present, he sees reasons for both hope and concern. On the hopeful side, far fewer people live in the back wards or large state institutions; increasing numbers of people with disabilities go to school, live, and work in their communities. He is concerned, however, by the fact that, in the community, some people are still very isolated and segregated. He concludes: "As they did in the 1840s, mentally retarded people who have money, supportive relatives, and understanding neighbors and employers do well in American communities. As they did in the 1840s, mentally retarded people who do not have those things, do not. For some, the community has become the beloved community; for others, the lonely crowd."

TITLE: Ideological, political, and legal principles in the community-living movement

AUTHOR: Turnbull, H. R.

PUBLICATION INFORMATION: 1988

In M. P. Janicki, M. W. Krause, & M. M. Seltzer (Eds.), Community residences for persons with developmental disabilities. Baltimore: Paul H. Brookes.

This chapter, written by a father of a young man with severe disabilities, provides a historical context and analysis of the six principles that have contributed to the development of the community living movement. Offshoots of the original principles of normalization, egalitarianism, and equal protection are 1) a new version of parens patriae, which holds that paternalism and altruism are best expressed by moving policy away from institutional placements; 2) anti-institutionalism, which seeks to abolish institutional placement; and 3) rebalanced power relationships between professionals and parents, on one hand, and people with disabilities on the other.

The author contends that the offshoot principles, though well-intended, have been misinterpreted in ways that may actually have contributed to the reversal of the original intention to assist people with disabilities. It is suggested that the challenge for the future lies in aggressive advocacy to ensure that improvements in habilitation, integration, interpersonal relationships and client choice become realities.

TITLE: Images of possibility

AUTHOR: Wertheimer, A.

PUBLICATION INFORMATION: 1986

Values in Action (formally Campaign
for the Mentally Handicapped)
Oxford House
Derbyshire
London, England E2 6HG

This report, published in Great Britain, poses themes around the issues we all grapple with related to the future for people with developmental disabilities. It asks, very simply, where we are we going and how we will get there. It systematically presents the issues inherent in the development of "people-oriented" services and describes options that presently exist in the U.S. and Canada. The author discusses lessons that people in Great Britain might draw from the options that are given. The report provides a short yet concise view into relevant topics and questions that we face today, challenging the assumption that people with developmental disabilities can only live with the constant support of special services.

TITLE: The origin and nature of our institutional models

AUTHOR: Wolfensberger, W.

PUBLICATION INFORMATION: 1975

Human Policy Press
P.O. Box 127
University Station
Syracuse, NY 13210

A chronicle of the attitudes, hopes and policies that led to the creation of institutions for people with mental retardation, this book explores common perceptions of people with mental retardation, such as pitiable, sick, menacing, innocent, angelic and, only rarely, as developing persons. Too often these attitudes implied a social response that gave rise to massive and inhumane institutions, always isolated from nearby communities. Through historical documents and an original photo essay, we begin to see the nature of institutional life.

The text bears relevance not only for its critique of institutions, but also for its explanations of ideologies and assumptions that underlie them. It is an essential manual for all who would promote deinstitutionalization and the principle of normalization in human services, in local communities, neighborhoods, and work places.

TITLE: The principle of normalization in human services

AUTHOR: Wolfensberger, W.

PUBLICATION INFORMATION: 1972

The G. Allan Roeher Institute
Kinsmen Building, York University
4700 Keele Street
Downsview, ON M3J 1P3
CANADA

As one of the most significant publications in the history of human services this book remains necessary reading for anyone involved in the provision of services. The first section delineates the conceptual and historical roots of our society's traditional approach to providing services to people with mental retardation. The principle of normalization is defined and proposed as an alternative service ideology which can avoid the pitfalls of the dehumanizing practices of the past. Some of the major implications of this principle are briefly explored. In the second section the implications of the principle of normalization for a wide range of concerns, from architecture to sex, are explored. The final section explores normalization as an impetus for generic services, citizen advocacy, monitoring of services, and direct financial support for handicapped persons.

TITLE: Cultivating thinking hearts: Letters from the Lifesharing Safeguards Project

AUTHORS: Zipperlen, H., & O'Brien, J.

PUBLICATION INFORMATION: 1994

Kimberton, PA: The Lifesharing Safeguards Project, Camphill Village Kimberton Hills. (Available from the Center on Human Policy)

This paper is an exploration of the rich mix of concepts that arise from and apply to the creation of effective safeguards for lifesharing households (where people with and without disabilities choose life together). It includes essays and letters from the different perspectives of people involved in these situations.

ADMINISTRATIVE ISSUES

This part of the Annotated Bibliography consists of three sections dealing with administrative issues:

1. Service Organization, Financing, and Systems Change
2. Planning and Developing Support with Individuals
3. Promoting Quality

There are hundreds, perhaps thousands, of books and articles on administrative issues, both in general and specific to developmental disabilities services. The resources annotated in these three sections were selected as useful materials for administrators of developmental disabilities services. On the other hand, we believe that administrators must be informed about many more issues than those covered in these sections, and would hope that administrators and others will familiarize themselves with resources that begin with the individual and his or her family and community.

1. Service Organization, Financing, and Systems Change

TITLE: Keep the promise: Managed care and people with disabilities

AUTHORS: American Network of Community Options and Resources, in collaboration with the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota

PUBLICATION INFORMATION:

American Network of Community Options
and Resources (ANCOR)
4200 Evergreen Lane, #315
Annandale, VA 22003

While discussions of managed care and cost cutting are occurring across the United States, Minnesota stands out as having developed a positive process for creating a managed care system for supporting people with developmental disabilities. This monograph includes a detailed review of the process and the lessons that were learned

during the long, sometimes tedious, group work. First, several lessons are presented about working as a "community"; next, a number of lessons about the group process are offered.

This monograph includes three appendices. The first gives a "record of the discussion" about advantages and disadvantages of what exists in Minnesota, of what is needed, and what can be developed. The second appendix contains "A Plan of the Developmental Disabilities Community for a Cost-Effective Quality Future for Minnesotans with Developmental Disabilities." Finally, the third appendix is the "Developmental Disabilities Community Principles, Values and Indicators Proposal Review Form."

While this monograph is based on managed care in Minnesota, the information may be very useful to other states that are working to develop responsive managed care systems.

TITLE: Health care financing for severe developmental disabilities

AUTHORS: Birenbaum, A., Guyot, D., & Cohen, H. J.

PUBLICATION INFORMATION: 1990

American Association on Mental Retardation (AAMR)
444 North Capitol Street, NW, Suite 846
Washington, DC 20001-1570

Despite recent reforms to health care provision for children with disabilities, the return of these children to their communities, and a voice to their families, "assurance of access to services and equitable means for meeting the expense" remain fragmented and ultimately incomplete. The fourteenth book in a series of AAMR Monographs, this monograph describes a multi-methodological study of the utilization, expenditures, and financing of health care for children and young adults with two types of mental disabilities: autism and severe or profound mental retardation. Specifically, this study of over 600 children aimed to "develop estimates of the patterns of health care utilization, expenditures...[and] to develop policy alternatives that will improve health care while containing costs." Annual expenditures for families of children with disabilities, financial burden on families, patterns of financing for health care, traditional paid and unpaid services for families, and family hardship are discussed. The researchers conclude that, "inequities abound in the financing of health care," and they suggest a number of policies that could correct these inequities relatively inexpensively.

TITLE: The state of the states in developmental disabilities (4th ed.)

AUTHORS: Braddock, D., Hemp, R., Bachelder, L., & Fujiura, G.

PUBLICATION INFORMATION: 1995

American Association on Mental Retardation (AAMR)
444 North Capitol Street, NW, Suite 846
Washington, DC 20001-1570

During the 1980s, David Braddock and his colleagues have produced national studies of public spending by the states for mental retardation and developmental disabilities services. This book is the third update of these studies, and is the most useful because, in addition to being current and comprehensive, it is hardbound and therefore sturdier than the first two documents. The first section describes the study and provides analyses of spending across states. The second section of the book contains hundreds of charts and other graphics that depict state spending for residential and community services and break down each state's expenditures, revenue sources, population trends, and other critical factors. Charts depicting each state's MR/DD spending per $1,000 per capita income and concise descriptions of the state's programs allow quick comparisons of state efforts and trends. The third section provides supplementary financial and programmatic data, such as state-by-state information on income maintenance programs (federal and state SSI, child disability benefits for adults disabled in childhood), special education services, and vocational rehabilitation services.

This critical reference provides answers to questions regarding where federal and state dollars are going and how states compare with one another, and is the most comprehensive and detailed analysis of public expenditures published to date.

TITLE: Creating individual support for people with developmental disabilities: A mandate for change at many levels

AUTHORS: Bradley, V. J., Ashbaugh, J. W., & Blaney, B. C. (Eds.)

PUBLICATION INFORMATION: 1994

Baltimore: Paul H. Brookes Publishing Co.

This book addresses the need for change at all levels of the service system in the effort to develop integrated services. It is organized in five major sections. The first section contains chapters which offer a history and rationale for the evolution of a new service paradigm of individualized supports. Chapters in the second section focus on

issues of conceptual change. The third section, "Change Throughout the System," includes chapters which describe examples of organizational and systems change. The fourth section, "Leadership and Empowerment," contains chapters related to advocacy and grassroots change. Finally, Section Five, "Mechanisms for Change," discusses issues such as planning, quality assurance, legislation, and implications for future practice and systems design.

TITLE: Developing financial incentives for placement in the least restrictive alternative

AUTHORS: Copeland, W. C., & Iversen, I. A.

PUBLICATION INFORMATION: 1985

In K. C. Lakin & R. H. Bruininks (Eds.), Strategies for achieving community integration for developmental disabled citizens. Baltimore: Paul H. Brookes Publishing Co.

The authors of this chapter suggest that the way most states and the federal government fund services for people with developmental disabilities tends to be uncoordinated and may actually hinder integration. A strong case is made for an approach to funding which is tied to individuals rather than solely to programs. A model state budget is used to show how funds can be redirected in a manner which will support integration.

TITLE: The cost of program models providing personal assistance services (PAS) for independent living

AUTHOR: Engley, L.

PUBLICATION INFORMATION: 1994

World Institute on Disability
510 Sixteenth St., Suite 100
Oakland, CA 94612-1500

This report describes six program models that provide personal assistance services to people with disabilities. Each model is scrutinized in terms of cost, which is a public expenditure, and degree of independent living that is provided to consumers. These six examples of personal assistance services show the range of models available, and how states and agencies can define the concept of independent living for individuals. Many issues are considered, including whether the consumer of personal

assistance services can choose a provider or agency from which to receive services, and the amount of control the consumer has regarding the type of service provided, hiring and firing issues, and paying the attendant. The report concludes that there was a major difference between programs that used individual providers and agency programs. Agency programs offered less support for independent living, and cost about twice as much as individual providers, mostly due to increased administrative costs.

TITLE: Parent power: Change through grassroots networking

AUTHORS: Farber, A., & Marcel, K.

PUBLICATION INFORMATION: 1994

In V. J. Bradley, J. W. Ashbaugh & B. C. Blaney (Eds.), Creating individual supports for people with developmental disabilities: A mandate for change at many levels. (pp. 373-285). Baltimore: Paul H. Brookes Publishing Co.

This book chapter describes an effort driving by parents in Louisiana to change the state's service system. In the late 1980s many parents in this state were frustrated with the lack of alternatives to institutionalization that existed for their children with severe disabilities. Beginning in 1988, parents joined other advocacy groups and policy makers to develop a vision of family support and supported living, design and push through supportive legislation, secure funding, and develop services. This chapter describes those efforts as well as the lessons learned from parent involvement in changing the service system.

TITLE: Direct dollars: A study of individualized funding in Canada

AUTHOR: G. Allan Roeher Institute

PUBLICATION INFORMATION: 1993

The G. Allan Roeher Institute
4700 Keele Street, Kinsmen Building
North York, Ontario M3J 1P3
CANADA

This book describes research that was part of a series of studies conducted by the Roeher Institute on the creation of a service system in Canada that is directed by the people receiving services as well as more equitable and cost-effective. This study

focuses on individualize funding, or the practice of giving money directly to people with disabilities and their families. It describes the general concept of individualized funding and examines current funding arrangements and their relation to individualized funding. It explores specific models of individualized funding and analyzes the implications of individualized funding from the perspectives of consumer, service providers, social service agencies, and the social welfare field. This study also briefly explores the applicability of individualized funding to other types of services such as vocational services, housing, child care, transportation, and education.

TITLE: Nothing personal: The need for personal supports in Canada

AUTHOR: G. Allan Roeher Institute

PUBLICATION INFORMATION: 1993

The G. Allan Roeher Institute
4700 Keele Street, Kinsmen Building
North York, ON M3J 1P3
CANADA

This book focuses on personal supports in Canada; however, many of the issues raised are relevant in the U.S. The first two chapters describe the framework within which personal supports are provided in Canada. Chapter 3 analyzes three fundamental problems with personal supports: access (problems of availability, complexity, and affordability); eligibility (problems in gaining entry to the system); and responsiveness (problems within the system). Finally, Chapter 4 presents policy options to address the issues raised in Chapter 3.

TITLE: The power to choose: An examination of service brokerage and individualized funding as implemented by the Community Living Society

AUTHOR: G. Allan Roeher Institute

PUBLICATION INFORMATION: 1991

The G. Allan Roeher Institute
4700 Keele Street, Kinsmen Building
York University
North York, ON M3J 1P3
CANADA

The power to choose is an examination of the impact of service brokerage and individualized funding on achieving the aim of self-determination, autonomy, and dignity for individuals labeled with an intellectual disability. Specifically, service brokerage is "a mechanism to deliver the planning resources that individuals require to arrange and purchase community supports and services. Service brokers assist individuals and their families in defining needs, provide information about alternative support and service options, etc." Through service brokerage, it is hoped that the individuals will be able to determine as fully as possible the decisions affecting his or her life. Specific topics discussed in this book include: making decisions for yourself, access to planning resources and planning in general, access to financial resources, accountability to individuals, and availability of community-based resources.

TITLE: Service brokerage: Individual empowerment and social service accountability

AUTHOR: G. Allan Roeher Institute

PUBLICATION INFORMATION: 1987

The G. Allan Roeher Institute
4700 Keele Street, Kinsmen Building
York University
North York, ON M3J 1P3
CANADA

Service brokerage, a concept that has been discussed for years, has been operationalized in British Columbia and is described in this small manual. In British Columbia, the concept was developed by parents of people with disabilities and is based on the belief that the standard ways of providing and funding services are inadequate. Service brokerage attempts to make systems more accountable to the people served by them and to put decision making control in the hands of these people and their support networks.

This monograph provides a comprehensive overview of the service brokerage concept and clarifies some of its critical operational aspects. Brokerage is described as one dimension of a three component "support nucleus." The "three inseparable components which complement each other" include: (1) the personal network; (2) individualized funding which ties dollars to the individual; and (3) an autonomous planning vehicle, acting as a fixed point of responsibility for planning and providing service brokerage as required to the individual who is supported by his or her personal network. "The support nucleus is in turn designed to function within the overall patchwork of services and supports provided by society to its citizens."

TITLE: Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities

AUTHORS: Hayden, M. F., & Abery, B. H. (Eds.)

PUBLICATION INFORMATION: 1994

Baltimore: Paul H. Brookes Publishing Co.

"As community participation and empowerment of persons with developmental disabilities change the very nature of service delivery, service providers are challenged to find the means and strategies to furnish services and supports that fit the unique needs of the individual rather than asking the individual to conform to the constraints of the services." This edited book is based on a second wave of community living research in which the researchers were participants, rather than the traditional observers. It is divided into four parts. Chapters in Part I address approaches to community living research, with an introductory chapter providing an overview of the community living concept. The three chapters in Part II discuss social relationships and community integration. Part III, Community Services and Support Issues, contains chapters that deal with issues related to costs and financing, staff training and retention, among others. Finally, the five chapters in Part IV, "Enhancing Independence and Autonomy," discuss self-determination, multicultural issues, legal guardianship, and supported employment.

TITLE: IMPACT: Feature issue on institution closures

AUTHORS: Hayden, M. F., Lakin, K. C., & Taylor, S. (Eds.)

PUBLICATION INFORMATION: 1995-1996

Minneapolis: Institute on Community Integration, University of Minnesota.

This issue of IMPACT contains a wide variety of articles about institutional closure. It includes articles about the realities of institutions by people with disabilities, description of a national effort by self-advocates to promote institution closure, parent perspectives on deinstitutionalization, national trends in institution closure, and deinstitutionalization litigation. It also contains articles describing specific processes of institution closure (e.g., Brandon Training School, in Vermont), as well as articles discussing the development of community services in conjunction with institution closure.

TITLE: Creative financing of community services: The state agency perspective

AUTHORS: Hemp, R., Braddock, D., Bachelder, L., & Haasen, K.

PUBLICATION INFORMATION: 1990

University Affiliated Program
in Developmental Disabilities
University of Illinois at Chicago
1640 West Roosevelt Road, M/C 626
Chicago, IL 60608

Defining creative financing as "coordinating multiple governmental and private sector funding sources in the development and maintenance of effective systems of community services for individuals with mental retardation/developmental disabilities," this monograph presents the perspectives of the principal mental retardation/developmental disabilities agencies in 20 states. The 20 states selected for the survey represented those judged to be most committed to and involved in delivery of community services, and the survey questions focused on the range of services and supports which constitute an "open" community system.

This monograph presents data on states' use of federal, state, and private sector funding sources as well as a series of recommendations for future development. The respondents, most of whom were directors of state offices, identified factors that have encouraged community service development, described state and local factors contributing to funding for community services, and defined federal, state and local governmental and private sector constraints in the development of community services. The responses of these 20 state agencies give cause for hope: it appears that states are looking for ways to promote integration, individualization, and flexibility in funding and service delivery as they work with providers, families, and people seeking services. A subsequent survey and report will address the perspective of private, community-based provider organizations.

TITLE: Jay Nolan Community Services: The advantages and dilemmas of converting quickly from group homes to supported living services

AUTHOR: Hulgin, K.

PUBLICATION INFORMATION: 1996

Syracuse, New York: Center on Human Policy, Syracuse University.

Jay Nolan Community Services is a nonprofit organization that provides a range of services to people with autism and other developmental disabilities in Los Angeles, California. Since January 1993, this agency has made remarkable changes in the way that it provides residential services. It has moved from operating group homes to supporting people to live in their own homes. This report, based on a visit in November 1995, describes this process of change.

The first section outlines the agency process of transition from group homes to supporting people in their own homes. This section includes a discussion of significant opportunities and strategies that contributed to the agency's success in this relatively quick change process, including: (1) learning from other agencies that had been successful in developing supported living services; (2) culturing the commitment and skills of a team of staff; (3) clarifying issues related to decision making power; (4) giving families opportunities to learn about supported living; and (5) agreeing to shift to supported living services without asking for increased state funding.

The following section describes ways in which the agency has begun to identify and respond to the needs and preferences of individuals over the long term, including: implementing circles of support; rearranging staff responsibilities; providing continuous opportunities for learning; and working to gain system support. Another section describes some specific changes that have occurred in a few people's lives. And, the report ends with a summary of lessons that have emerged from implementing a supported living approach in this agency.

TITLE: The journey to inclusion: A resource guide for state policymakers

AUTHORS: Jaskulski, T., Lakin, K. C., & Zierman, S.

PUBLICATION INFORMATION: 1995

President's Committee on Mental Retardation
Administration for Children and Families
Cohen Building, Room 5325
330 Independence Avenue, S.E.
Washington, DC 20201

This report begins with a discussion of the changing responses to people with mental retardation in order to provide a context for thinking about the journey to inclusion. It opens with the thoughts of people with mental retardation and their family members on the importance of inclusion, followed by an overview of trends toward inclusion in the service system and the evolution in our understanding of what is important to people with mental retardation. Chapter 2 summarizes the concept of mental retardation and provides information on prevalence. Chapters 3 and 4 focus on inclusion throughout the life span with many stories and examples about individual people and from many different states and localities. Chapter 5 focuses more

specifically on supports, at the level of the individual, family, and communities and systems. The final chapter emphasizes the importance of empowerment, and includes many statements from self-advocates. Resources for further information are provided in each chapter, as well as in the Appendices.

TITLE: Medicaid services for persons with mental retardation and related conditions

AUTHORS: Lakin, K. C., Jaskulski, T. M., Hill, B. K., Bruininks, R. H., Menke, J. M., White, C. C., & Wright, E. A.

PUBLICATION INFORMATION: 1989

Minneapolis: Center for Residential and Community Services, Institute on Community Integration, University of Minnesota.

This report describes a major research project funded by the Health Care Financing Administration (HCFA) to examine policy related trends and projections in the use of various Medicaid-funded services for persons with mental retardation and to identify factors influencing these trends nationally and in the various states. The project made a longitudinal analysis of extant data bases on residential services, surveyed all state MR/DD agencies, and prepared case studies of 10 states. This report examines general trends in residential services nationwide, status and trends in intermediate care facilities (ICF/MRs), use of the Medicaid waiver (Home and Community-Based Services) in states, placement of people with mental retardation in nursing homes, and the use of other Medicaid options.

A valuable aspect of this report is that it points out that community services have become the norm in most states, and that state directors are interested in expanding and improving community living options. According to this report, state directors contend that the states need and are seeking expanded federal participation in these endeavors, and are asking for changes in Medicaid, whether in the form of reductions in the restrictions in HCBS requirements or in passage of Medicaid reform legislation. The last few pages of the report detail the problems currently facing states with attention to how the two current Medicaid reform bills respond to them.

TITLE: Medicaid managed care: An advocate's guide to protecting children

AUTHORS: Langill, D., Dubois, S. K., Martin, K., Perkins, J., & Rivera, L.

PUBLICATION INFORMATION: 1996

National Association of Child Advocates
1522 K Street, N.W., Suite 600
Washington, DC 20005

This manual is designed for use by a broad audience, from experts in children's health care to novices seeking to understand the complexities of Medicaid and managed care. The manual contains information that ranges from a basic overview of the Medicaid program, to complex and technical information on various aspects of managed care, to descriptions of successful advocacy strategies.

The chapters of the manual are divided into two sections: chapters in Section I present programmatic and technical information about the Medicaid program, managed care, and state Medicaid managed care programs, while chapters in Section II discuss ways that advocates can influence the development and implementation of Medicaid managed care programs in their states and localities. The manual also includes a series of appendices that contain additional information and resource materials that address Medicaid, managed care, and advocacy on behalf of children and other Medicaid beneficiaries.

TITLE: Supported living monograph, Volume II

AUTHOR: National Association of Private Residential Resources

PUBLICATION INFORMATION: 1992

NAPRR
4200 Evergreen Lane, Suite 315
Annandale, VA 22003

This monograph was prepared for a conference on Supported Living sponsored by NAPRR in February, 1992. It includes a book chapter by Jay Klein on home ownership, an article by John O'Brien and Connie Lyle O'Brien about organizational issues related to supported living, and several other articles. The appendix includes lists of other resource materials.

TITLE: "Perspectives" and "Community Services Reporter"

AUTHOR: National Association of State Directors of Developmental Disabilities Services, Inc.

PUBLICATION INFORMATION: Monthly

NASDDDS
113 Oronoco Street
Alexandria, VA 22314

These monthly publications include articles about general issues in developing community services and innovative practices around the country. Each issue also contains resources such as publications, videos, and conferences.

TITLE: An affirmation of community: A revolution of vision and goals

AUTHORS: Nerney, T., & Crowley, R. F.

PUBLICATION INFORMATION:

Monadnock Developmental Services
Region V Area Agency
Keene, NH

In 1993, Monadnock Developmental Services, a non-profit regional agency in New Hampshire, was awarded a grant from the Robert Wood Johnson Foundation for the purpose of creating a local system of services that supports self-determination. This monograph was developed as a plan or guide in that process. It provides an overview of the values and vision of the agency and six specific goals including: self-determined personal supports, integrated housing, elimination of the congregate model, inclusive education, equal access to employment, and universal physical accessibility. The second part of the monograph describes how the system and funding mechanisms would have to change to support a service plan that is developed by individuals and the people closest to them. The concepts of circles of support, service brokerage and individualized funding are emphasized.

TITLE: Remembering the soul of our work: Stories by the staff of Options in Community Living, Madison, Wisconsin

AUTHORS: O'Brien, J., & Lyle O'Brien, C. (Eds.)

PUBLICATION INFORMATION: 1992

Options in Community Living
22 North Second Street
Madison, WI 53704

This is a collection of 150 stories written between 1987 and 1991 by staff from Options in Community Living of Madison Wisconsin, an agency that pioneered the supported living movement. Their stories effectively communicate some of the qualities that make their work meaningful.

TITLE: More than just a new address: Images of organization for supported living agencies

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1991

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

In this paper, O'Brien and Lyle O'Brien explain the need for new ways of thinking about organizations and of organizing to implement a supported living approach. They explain that supported living involves a new mindset in working with people, one which is not compatible with many existing service organizations. More responsive organizations will facilitate positive relationships with people receiving services and the opportunity for continuous learning from the effort to support them. The paper includes ideas for building new structured uses of power within agencies. For example, it describes a new way of building effective teams and responsibilities of directors. The paper concludes with a discussion of the need to view organizations as social units rather than the traditional machine image if these changes are to be implemented successfully.

TITLE: Liability issues affecting consumer-directed personal assistance services: Report and recommendations

AUTHORS: Sabatino, C.P., & Litvak, S.

PUBLICATION INFORMATION: 1995

World Institute on Disability
510 Sixteenth St., Suite 100
Oakland, CA 94612-1500

This report identifies two policy challenges in the area of personal assistance services for people with disabilities: cost of services and program design. Liability is an important part of both of these issues. Liability can include employment taxes and benefits such as worker's compensation and unemployment insurance, personal injury

due to negligence, and provider certification and licensure requirements. These liabilities and other legal obligations affect the way personal assistance services are offered. This report addresses these concerns from different competing groups: consumer, service sponsor, service provider, and regulator. Several specific issues are identified under each section of liability and recommendations are provided that will help agencies and government provide better personal assistance services to people with disabilities.

TITLE: Supported living: New directions in services to people with developmental disabilities

AUTHOR: Smith, G.

PUBLICATION INFORMATION: 1991

NASDDDS
113 Oronoco Street
Alexandria, VA 22314

This volume provides a comprehensive summary of supported living nationwide. It includes an overview of supported living, and chapters on various state supported living programs, approaches to financing supported living, and the lessons being learned as states implement supported living programs.

TITLE: Managed care and people with developmental disabilities: A guidebook

AUTHORS: Smith, G., & Ashbaugh, J.

PUBLICATION INFORMATION: 1995

NASDDDS
113 Oronoco Street
Alexandria, VA 22314

The move from the traditional Medicaid program as a means of providing supports for persons with developmental disabilities is being replaced with the newer Managed Care "system." These changes are forcing us to rethink how to structure systems to deliver supports to individuals with disabilities both economically and efficiently. This guidebook is intended to help individuals make the transition to the managed care system while at the same time incorporating the "overarching goals of inclusion and self-determination for people with developmental disabilities." Included in this guidebook are the sections: an overview of managed care, managed care in the

States, managed health care and people with developmental disabilities, long-term care and supports, strategic issues concerning long-term supports, managed care models, a managed care feasibility study and plan, and a description of several plans already in existence across the US.

TITLE: Coming home: From deinstitutionalization to supporting people in their own homes in Region VI, New Hampshire

AUTHOR: Walker, P.

PUBLICATION INFORMATION: 1993

Syracuse, NY: Center on Human Policy, Syracuse University.

This report describes the efforts of the Area Agency for Developmental Services in Region VI, New Hampshire to shift from supporting people in group homes to supporting them in their own homes. It offers important lessons for agencies/regions facing the dual challenge of institutional closure and promoting quality of life in the community.

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2. Planning and Developing Supports with Individuals

The ability of people with the most severe disabilities to live and flourish in the community is largely dependent on the availability of individualized and flexible services and supports. The resources in this section provide conceptual frameworks, service principles, and strategies and resources to use in managing and coordinating a comprehensive system of services. Other materials on planning and coordination of specific services are annotated in the "services and supports" sections.

TITLE: Getting to know you: One approach to service assessment and planning for individuals with disabilities

AUTHORS: Brost, M. M., & Johnson, T. Z.

PUBLICATION INFORMATION: 1982

DHSS-DCS
P.O. Box 7851
Madison, WI 53707

This book describes one attempt to create an alternative approach to needs assessment and service planning for people with developmental disabilities. The authors don't believe that knowledge or understanding of a person's needs can be gained through administration of interview schedules, checklists or any other standardized procedures (most widely used in human services today). Instead they have developed an alternative and manageable way of gathering information that avoids treating people routinely or losing track of their uniqueness. This alternative approach to individual assessment and planning offers very helpful guidelines to insure that the services that are planned, purchased and delivered really respond to the individual's need.

The book is divided into two parts: Part I contains a description of the approach to need assessment and planning that was developed and refined during 1979-1981 by staff of the Developing Individualized Service Option Project in Wisconsin. Part II describes and critiques a training project carried out in LaCrosse, Wisconsin to teach people to use the need assessment and service planning process described in Part I.

The book is a very useful handbook for people whose jobs involve assessment/planning and for people involved in training others in assessment and planning. Much of the material is also a valuable resource for others, such as direct service providers, advocates, administrators, parents and consumers.

TITLE: Choices and obligations: A look at personal guardianship

AUTHOR: Centre for Research and Education in Human Services

PUBLICATION INFORMATION: 1988

Centre for Research and Education in Human Services
P.O. Box 3036, Station "C"
Kitchener, ON N2G 4R5
CANADA

This, one of a series of Policy Analysis Papers, is based on a day long meeting coordinated by the Centre for Research & Education in Human Services. The group in attendance represented consumers, parents, service providers, advocates, and community researchers as well as board members and staff of the Centre. As such, this paper presents a philosophical overview of the reasons for, dilemmas inherent in, and abuses occurring with the legal procedures known as guardianship. While Canadian law may differ from guardianship law in any given state in this country, many of the issues and dilemmas surrounding guardianship hold true here as well. Thus, this short paper is valuable because it frames these issues, discusses when and why intervention in an adult's life might be considered, and points out the complexities of establishing what is in the best interest of another.

Another good aspect of this paper lies in its discussion of the limitations of legislation and its exploration of the idea that expanded policies and community initiatives to create more responsive communities must accompany effective, nonintrusive guardianship legislation. It points out the many times in which nonguardianship responses are more appropriate and protective of individual rights than an automatic presumption of incompetency, and the many safeguards that should be employed if guardianship is used. The paper concludes with a variety of suggestions for guardians, policymakers, judges, and others concerned with the issues surrounding guardianship.

TITLE: Choice through knowledge, knowledge = power

AUTHORS: Cotton, P., & Sowers, J.

PUBLICATION INFORMATION: 1995

Patty Cotton
Jo-Ann Sowers

This manual was developed to provide an overview of services offered through an organization called Opus, Inc. in New Hampshire. The organization was formed in 1995 to assists individuals with disabilities and their families to determine the types of support they need and to get them either through formal or informal resources.

The emphasis of their efforts is on assisting people to understand and create alternative means of getting the supports they need such as hiring a service broker to find services through natural networks, professional business arenas, community services, and human service systems. Prior to choosing service providers, the agency assists individuals to define what they consider quality services and to conduct interviews with service providers. Once the providers are chosen, Opus, Inc. assists individuals and their families to secure the necessary funding which sometimes involves negotiating with the state. Finally, the agency assists people to evaluate the effectiveness of their supports over time.

Services through Opus, Inc. are paid for by the individual. Typically, funding agencies in New Hampshire allocate a sum of money to the individual to purchase facilitation and support for service planning.

TITLE: Building community one person at a time: One candle power

AUTHORS: Ducharme, G., Beeman, P., DeMarasse, R., & Ludlum, C.

PUBLICATION INFORMATION: 1994

In V. J. Bradley, J. W. Ashbaugh, & B. C. Blaney (Eds.), Creating individual supports for people with developmental disabilities: A manual for change at many levels. (pp. 347-360). Baltimore: Paul H. Brookes Publishing Co.

This chapter describes a project funded by the Connecticut Developmental Disabilities Council to implement the concept of circles of support with five individuals. Circles of support, as described here, consist of a six part process designed to improve the lives of individuals with disabilities. The process includes: 1) building on capacities of people and communities; 2) clarifying the vision and goals of the person with the disability; 3) building circles of supports; 4) building bridges to community life; 5) starting small, and; 6) changing the system. In this chapter, Demarasee (who lived in an institution) and Ludlum (who lived with her family) tell how this process has helped them to move to homes of their own and gain membership in their communities.

TITLE: Reuniting families: A resource guide for family involvement in the closing of institutions

AUTHOR: Farlow, D.

PUBLICATION INFORMATION: 1987

Family Support Institute
300-3 East 6th Avenue
Vancouver, BC, V5T 4P4
CANADA

This booklet is a companion volume to Return to the community: The process of closing an institution, produced by the Centre for Research & Education in Ontario. It is based on information collected for the study reported on in that volume, and provides hopeful and specific information on reinvolving families whose ties to their family member may have been attenuated or eliminated through a long institutionalization. This book is a must for anyone involved actively in deinstitutionalization, and for those working with people who have left institutions but have little family involvement. The book is written for, and from the point of view of, families but has great relevance for professionals seeking to understand family reluctance and fears about deinstitutionalization.

TITLE: Creating responsive communities: Reflections on a process of social change

AUTHOR: Lord, J.

PUBLICATION INFORMATION: 1985

Ontario Association for the Mentally Retarded
376 Bayview Avenue
Toronto, Ontario M4G 3A3
CANADA

This monograph is about the struggle to create more responsive communities for people with developmental handicaps and their families. In Ontario, Canada, this struggle took the form of ComServ, an acronym for comprehensive, community-based services, a social change strategy developed in 1972. In its simplest form, the goal of ComServ is to provide every handicapped individual with a place in their community where they can go to be assured that high quality services which are comprehensive to

their needs will be developed. In another sense, ComServ is about how regions can plan services with individuals and families to ensure that services are valued, individualized, and as integrated as possible.

This monograph has three major sections. Part One documents the history of the ComServ movement in Ontario, including an analysis of the various initiatives which led people in the 1970s to be concerned about issues which go beyond direct service provision. Part Two provides an analysis and assessment of more recent critical issues and actions from the social change process, including major themes, principles, and processes which have worked and some of those which have faced difficulties. And finally Part Three reflects on how the nature of ComServ has been revised as people's understanding has expanded and as political-economic contexts have changed.

TITLE: Return to the community: The process of closing an institution

AUTHORS: Lord, J., & Hearn, C.

PUBLICATION INFORMATION: 1987

Centre for Research and Education in Human Services
P.O. Box 3036, Station C
Kitchener, ON N2G 4R5
CANADA

This is an excellent qualitative study of the experiences of people with mental retardation, their families, governmental officials and human service workers involved in the closure of an institution in British Columbia. Throughout the work, ordinary language and dozens of quotations by the people affected are used to discuss and ground the themes that emerged during the course of the study. The findings will be of value to anyone considering change from one form of human service to another, and of special interest to those who are thinking about closing an institution. As readers we are first introduced to the families, residents, and workers and their feelings about and investment in the institution. Next, we move through the process from July 8, 1983, when the government announced the institution would close, to its actual closure 18 months later. Finally, we see how the men and women who left are faring one year later in their services in the community. We see the inadequacy of the planning that usually went into the process, and thereby learn of the importance of careful planning and involvement of families, even families who seem no longer connected to their family member. We learn how eager the families, staff, and community groups were to be involved in the planning, and of the many ways in which some of the parties engaged people in the process. The study documents many weaknesses in the community services that resulted from the process, including their reliance on group homes as the preferred way for people to live in the community and the lack of awareness of the importance of social interaction and social integration for the people

who moved back to their home communities. It also documents many benefits of the move for the people affected. This is "must" reading for policymakers and workers hoping to be involved in major social change efforts.

TITLE: Capacity works: Finding windows for change using personal futures planning

AUTHOR: Mount, B.

PUBLICATION INFORMATION: 1995

The Community Place
730 Main Street
Manchester, CT 06040

This is a workbook designed to assist people with disabilities, their families, and allies to help clarify their thinking and focus their efforts in the process of personal futures planning. It describes six "windows" that can help guide people through the process of developing a vision and a strategy for action. The windows include: listening to hope; expanding and deepening relationships; recognizing and developing preferences; finding opportunities in community life; developing a future vision; and understanding my struggle. For each window, the workshop presents discussion, examples, and reflection tasks to help guide group discussion.

TITLE: Person-centered planning: Finding directions for change using personal futures planning

AUTHOR: Mount, B.

PUBLICATION INFORMATION: 1992

Graphic Futures, Inc.
25 West 81st Street, 16-B
New York, NY 10024

This booklet presents the values and philosophy of person-centered planning in comparison with traditional practices. It includes a description of the planning process and the implications for long term change for individuals and organizations.

TITLE: It's never too early, it's never too late: A booklet about personal futures planning

AUTHORS: Mount, B., & Zwernik, K.

PUBLICATION INFORMATION: 1988

Metropolitan Council
Mears Park Centre
230 East Fifth Street
St. Paul, MN 55101

This booklet provides a good overview of personal futures planning. It begins with a comparison of this approach with traditional planning methods. Then, through personal examples, the booklet describes the components of the actual planning process, including many illustrations. The last section discusses the role of personal futures planning in relation to Individual Habilitation Plans and in promoting systems change.

TITLE: A guide to life-style planning: Using The activities catalogue to integrate services and natural supports.

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1987

In B. Wilcox & G. T. Bellamy, (1987) A comprehensive guide to *The activities catalog: An alternative curriculum for youth and adults with severe disabilities* (pp. 175-189). Baltimore: Paul H. Brookes Publishing Co.

O'Brien presents life-style planning as a process that guides family members, friends, and service providers through three essential planning activities: 1) describing a desirable future with the person with a disability; 2) developing a schedule of activities and supports that will organize available resources to move toward the future; and 3) accepting responsibility for using available opportunities and dealing with the lack of needed activities and supports. This approach is based on the understanding that there are five basic accomplishments that should guide services for people with severe disabilities: community presence, community participation, choice, respect, and competence.

TITLE: Finding a way toward everyday lives: The contribution of person centered planning

AUTHORS: O'Brien J., & Lovett, H.

PUBLICATION INFORMATION: 1992

Harrisburg, PA: Pennsylvania Office of Mental Retardation.
(Available from the Center on Human Policy)

This monograph begins with a description of the foundations of person centered planning. "The term, person centered planning, refers to a family of approaches to organizing and guiding community change in alliance with people with disabilities and their families and friends." Next is a discussion of how person centered planning influences change by: creating a compelling image of a desirable future and inviting people to join with the focus person to make it happen; strengthening personal relationships; and helping people plan, act, and learn by reflecting on their successes and failures. The authors then discuss some limitations of person centered planning, as well as controversies among people engaged in person centered planning. They then discuss fears about the debasement of person centered planning, and offer some possible safeguards related to this. The monograph concludes with discussion about distinctions between various approaches to person centered planning (e.g., individual service design, personal futures planning, MAPS, essential lifestyle planning) and brief comment about the future of person centered planning.

TITLE: Framework for accomplishment: A workshop for people developing better services

AUTHORS: O'Brien, J., & Lyle, C.

PUBLICATION INFORMATION: 1988

Responsive Systems Associates
58 Willowick Drive
Lithonia, GA 30038

This is an excellent week-long workshop for service providers and others interested in developing better ways of supporting people to live in the community. The workshop emphasizes accomplishments and valued experiences that apply to most people in our society, and leads the participant to discover ways of supporting one person to achieve these accomplishments and experiences. Participants work in teams, each participant in a team getting to know one person with a disability. The team

develops profiles for desired futures for the people they have come to know, and works together to define constructive actions that could be taken by the program serving that person. This is an intense and creative experience, very enjoyable for participants and for the agencies that volunteer as sites for the workshop. The manual for the workshop cannot be purchased separately.

TITLE: Telling new stories: The search for capacity among people with severe handicaps

AUTHORS: O'Brien, J., & Mount, B.

PUBLICATION INFORMATION: 1989

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

This article tells the story of a man from two perspectives. It contrasts the story told by traditional service plans with the effort to understand his life from a personal and capacity based perspective. The two stories differ in the way they were constructed, in their purpose, in their consequence, and in the assumption they shape about human development and human service organization.

TITLE: PATH: A workbook for planning positive possible futures

AUTHORS: Pearpoint, J., O'Brien, J., & Forest, M.

PUBLICATION INFORMATION: 1993

Inclusion Press
24 Thome Crescent
Toronto, ON M6H 2S5
CANADA

"The authors of PATH have a vision of a just world, rich with diversity, where every person's gifts are acknowledged, supported, valued; a world where everyone is included, belongs, and makes valued contributions." PATH is a planning process to assist people and organizations achieve that vision. This booklet begins with an introduction to PATH. It then discusses the eight steps that define the PATH process: (1) touching the dream; (2) sensing the goal; (3) grounding in the now; (4) identifying people to enroll; (5) recognizing ways to build strength; (6) charting action for the next few months; (7) planning the next month's work; and (8) committing to the first step. Description of each step includes numerous examples and illustrations.

TITLE: A handbook for people thinking about moving

AUTHOR: People First of Washington

PUBLICATION INFORMATION: 1990

People First of Washington
P.O. Box 381
Tacoma, WA 98401

People with developmental disabilities who are thinking about--or being projected for--a move from one place to another (nursing home or institution to community, group home to apartment, etc.) may need assistance in making informed choices about the options available to them. This handbook can be used by anyone, including a member of a self-advocacy group, to help someone understand and decide about a new home. The user goes through a process that includes four steps: 1) knowing one's rights about moving; 2) making a list of what one wants in life; 3) looking at, visiting, and comparing all the choices to what one wants; 4) making a decision without pressure. The handbook is laid out for use as a workbook, so that users could write in it as they go through the steps. It could also be used by an individual's family and friends, if they are needed to help with the decision-making process. Each step asks a large number of concrete questions that should help users develop a vision of what is wanted and to compare that vision with an actual place. While this handbook uses a few state-specific terms, it is nevertheless an excellent resource for anyone interested in planning with an individual with developmental disabilities.

TITLE: Supporting people with severe reputations in the community

AUTHOR: Smull, M., & Harrison, S.

PUBLICATION INFORMATION: 1992

NASDDDS
113 Oronoco Street
Alexandria, VA 22314

This handbook describes, using many practical examples, how people receive "severe reputations," how planning can be implemented with an individual for community living, how supports to implement the plan can be recruited, and how the frequent perversions of supported living for people with more severe disabilities can be avoided.

TITLE: Reviewing essential lifestyle plans: Criteria for best plans

AUTHORS: Smull, M. W., Sanderson, H., & Harrison, S. B.

PUBLICATION INFORMATION: 1996

Michael Smull
Support Development Associates
4208 Knowles Avenue
Kensington, MD 20895

This document presents criteria for determining "good" or "best" essential lifestyle plans. It first provides an overview of these criteria, which cover what type of information should be included in the plan, the language and detail of the plan, and the way that the plan is approached (e.g., "with" people rather than "for" people). Next, the paper provides detailed discussion and examples for each of the criteria, including possible headings to use, as well as the kind of information to include/not include. This document concludes with a discussion of additional issues to consider in developing and reviewing plans, including: looking beneath the surface; the importance of helping people have opportunities; helping people learn (the role of teaching); the use of graphics; whose voice to use; the plan as a means to an end.

3. Promoting Quality

Promoting quality, and ensuring that there are adequate yet nonintrusive safeguards in the lives of people who depend on services, are major concerns for administrators, advocates, parents, and people with disabilities. The paper by O'Brien, Lyle O'Brien and Schwartz annotated in the Perspectives section, What can we count on to make and keep people safe?, addresses many current concerns about how and whether quality can be assured. Some of the materials in this section promote the involvement of a range of reviewers or monitors, while others are instruments that can be used by citizen reviewers. It is most difficult to find quality assurance materials that address the concerns raised in the O'Brien et al. piece mentioned above. The irony is that quality assurance systems cannot assure, and may interfere with, the kinds of lives ordinary people want for themselves. Several of these materials acknowledge and discuss these problems and limitations.

TITLE: Reinventing quality - A sourcebook of innovative programs for quality assurance and service improvement in community settings (Rev. ed.)

AUTHORS: Blake, E. M., Prouty, R. W., Lakin, K.C., & Mangan, T.

PUBLICATION INFORMATION: 1994

Minneapolis: Research and Training Center on Residential Services and Community Living, Institute on Community Integration, University of Minnesota.

The fourth edition of this sourcebook revises and expands on earlier editions' descriptions of exemplary practices to assure and enhance the quality of service offered to individuals with developmental disabilities. Examples of groups providing exemplary services are divided into the following categories: statewide information and evaluation systems, service agency development, system-wide quality enhancement, values infusion, consumer and citizen monitoring, community relationship building technical assistance, personnel training and professional development, advocacy training and support for individuals and families, best practices, and quality assurance in community supported living. The names and contact information of each of these groups are given.

TITLE: Quality assurance for individuals with developmental disabilities: It's everybody's business

AUTHORS: Bradley, V. J., & Bersani, H. A. (Eds.)

PUBLICATION INFORMATION: 1990

Baltimore: Paul H. Brookes Publishing Co.

This edited book presents current, often divergent, perspectives on quality assurance. As Elizabeth Boggs points out in the foreword, the book does well at reflecting the chaos in the field of developmental disabilities. If quality assurance is everybody's business, how can the varying perspectives of all the players be reconciled? One very positive feature of the book is its inclusion of consumer and family members' perspectives. These chapters challenge readers to consider how consumers and family members can be meaningfully involved in assessing and assuring the quality of the services they receive. Other chapters address governmental, management, advocacy and accreditation issues, research, and quality assurance systems. A final chapter on the future points to the possibility of developing responsive quality assurance systems, of moving away from the present systems' reliance on basic regulatory approaches, far removed from the people whose lives are affected.

TITLE: Assessment and enhancement of quality services for persons with mental retardation and other developmental disabilities

AUTHORS: Lakin, K. C., Larson, S. A., & Prouty, R.

PUBLICATION INFORMATION: 1994

In M. F. Hayden & B. H. Abery (Eds.), Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities (pp. 207-230). Baltimore: Paul H. Brookes Publishing Co.

"People cannot only be degraded when other people care for them, but they can also be degraded if others do not care for them." This chapter will help those interested in promoting quality care for persons with disabilities to reflect on the challenges in developing appropriate quality assurance service practices. Components that the authors feel are important to comprehensive care include individual assessment and outcome monitoring, and promotion of individual choice. Four examples of promising practices in quality assessment and enhancement efforts are also provided.

TITLE: Assistance with integrity: The search for accountability and the lives of people with developmental disabilities

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1993

Lithonia, GA: Responsive Systems Associates
(Available from the Center on Human Policy)

Intended to be a polemic, this report focuses on persons with developmental disabilities who rely on service providers for 24 hour assistance. Topics discussed include: the current crises in accountability, barriers to thinking deeply about accountability, effective interdependence as an emerging perspective on the search for accountability, safety and effective interdependence, integrity as a central virtue in effective interdependence, threats to integrity, dealing more effectively with failures of integrity, the potential of "Total Quality Management," and integrity as a guide to policy.

TITLE: Options' policy on quality of life

AUTHOR: Options in Community Living

PUBLICATION INFORMATION: 1983

Options in Community Living
22 North Second Street
Madison, WI 53704

Options in Community Living, a support service agency for adults living in the community (see annotation for Belonging to the community, in the section on Community Living for Adults), prepared this policy statement to provide staff with standards for evaluating the well-being of people they support and for identifying areas where intervention might be needed. The policy statement is available as part of the manual, Belonging to the community. It covers areas such as personal income, housing, health, safety, appearance and hygiene, relating with others, meaningful activities, and mobility. For each of these areas, the policy identifies conditions that must exist to ensure that a person will not be at risk in the community and conditions that will further promote a valued lifestyle.

TITLE: A guide to program quality review of day programs (2nd ed.)

AUTHOR: Rammler, L.

PUBLICATION INFORMATION: 1986

State of Connecticut
Department of Mental Retardation
90 Pitkin Street
Hartford, CT 06108

This quality assurance instrument includes six sets of measures of program quality, including: a) presence and participation measures; b) good relationships measures; c) choice measures; d)respect and dignity measures; c) competence measures, and f) wages and benefits measures. These measures, based on the Connecticut Department of Mental Retardation's overall mission statement, promote values that the department, parents, and people with disabilities in Connecticut identified as important in peoples' lives. The guide includes explanations as to how each question should be applied to a program.

TITLE: Quality of life, Volume 1 - Conceptualization and measurement
Quality of life, Volume 2 - Application to persons with disabilities

AUTHOR: Schalock, R. L. (Ed.)

PUBLICATION INFORMATION: 1996

American Association on Mental Retardation (AAMR)
444 North Capitol Street, NW, Suite 846
Washington, DC 20001-1570

"Quality of life [QOL] is not a new concept." Today, what things bring quality to a life are a hot topic in the field of disability, compounded by the fact that QOL is a complex concept with multiple perspectives and dimensions. Schalock tells us that we are in the midst of a "paradigm shift" in the disability field on how we view and interact with people with disabilities. In the first volume, the reader is provided with the opportunity to reflect on the concept of QOL through discussions of self-advocacy, the individual's perspective, QOL across the life span, and parents' and grandparents' perspectives. The measurement of QOL independently and together with the conceptualization of QOL are also examined. The second volume continues with discussion of service delivery, organizational change, public policy application, and QOL and culture.

TITLE: PASSING: Program analysis of service systems' implementation of normalization goals

AUTHORS: Wolfensberger, W., & Thomas, S.

PUBLICATION INFORMATION: 1983

The G. Allan Roeher Institute
Kinsmen Building, 4700 Keele Street
York University
North York, ON M3J 1P3
CANADA

This book provides the guidelines for operationalizing the principle of normalization in an instrument for evaluating the quality of human services. In addition, the specific examples and discussion contained in this manual are intended to teach the principle of normalization to human service workers. The 42 PASSING ratings are broken down into two major categories: 1) Program elements related to client social image enhancement and 2) elements related to competency enhancement. Within both categories ratings are further subdivided as to whether they apply to a) the physical setting in which the service is located; b) the ways in which the service groups its clients and otherwise structures and supports relationships between them and other people; c) the activities, programs, and other ways in which the service structures the client's time; and d) miscellaneous other factors including language, symbolism, and imagery which the service attaches to its clients. All in all, the in-depth analysis encouraged by this resource guides the reader through a rigorous examination of any service setting.

SERVICES AND SUPPORTS FOR INTEGRATION

The resources in this division are grouped together because they deal directly with services and paid or formal supports, rather than with informal supports and advocacy. They also promote, in general, integration and community participation.

They are divided into the following sections:

1. Family Support
2. Permanency Planning
3. Community Living for Adults
    a. Support Issues
    b. Housing
4. Supporting People with Challenging Behaviors

We believe that readers should approach these sections with an additional commitment to explore resources on community, relationships, and other issues basic to all of our lives.

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1. Family Support

This subsection includes brief annotations of some resources on family support. There is a rapidly growing body of literature available today on family support; hence, the material covered here only represents a small portion of that which exists. This listing includes some of the materials that describe current and innovative trends in family support.

TITLE: Family care for persons with developmental disabilities: A growing commitment

AUTHORS: Agosta, J. M., & Bradley, V. J. (Eds.)

PUBLICATION INFORMATION: 1985

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

The report includes five concept papers on family support issues, including a parental perspective, the perspective of a person with a disability, an overview of the goals and purposes of family support services, a review of current options for family support policy, and a future policy directions statement. The appendices include a directory of 22 statewide family support initiatives and 11 organizations that offer parents financial planning services.

TITLE: Designing programs to support family care for persons with developmental disabilities: Concepts to practice

AUTHORS: Agosta, J., Bradley, V., Rugg, A., Spence, R., & Covert, S.

PUBLICATION INFORMATION: 1985

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

This report on family support services highlights the trends in the literature, presents the results of a 50 state survey (with case studies of six of the states), and includes information on the development of a family support policy in Virginia. Six key issues surrounding the development of family support services are discussed including the role of the family, program eligibility, service administration, permissible services, use of existing resources and facilities, and program evaluation.

The report is written primarily for professionals and service planners who are interested in the status of family support service programs in this country and in the major issues involved in their development.

TITLE: Home care manual series

AUTHOR: American Family Health Institute

PUBLICATION INFORMATION: 1986

Springhouse Corporation
111 Bethlehem Pike
Springhouse, PA 19477

This organization has produced a series of 32 page booklets which outline in clear jargon-free text and illustrations basic procedures in health care. The titles in the series include: Bedsores, Care basics, Cast care, Colostomy care, Comfort measures, Crutches and canes, Danger signs, Dressings and bandages, Exercises, Feeding tubes

and pumps, Help for the care giver, Hospital beds, Hygiene, Incontinence care, Injections, Medications, Oxygen therapy, Parenteral nutrition, Self-help aids, Suctioning, Tips for feeding the sick, Tracheostomy care, Urinary catheter care, and Walkers and wheelchairs. These are useful resources for non-medical personnel, family members, and people with special needs themselves.

TITLE: In support of families

AUTHOR: Biklen, D.

PUBLICATION INFORMATION: 1991

In S. J. Taylor, R. Bogdan, & J. A. Racino (Eds.), Life in the community: Case studies of organizations supporting people with disabilities (pp. 35-53). Baltimore: Paul H. Brookes Publishing Co.

This chapter describes family supports provided in the Macomb-Oakland area of Michigan from the perspective of families who receive supports. It begins with an introduction to some families and describes some of their perspectives on their children, household work, and professionals. It discusses, from the perspectives of the families, both the positive aspects of the family support program as well as the dilemmas, including mothers' roles, relationships with professionals, intrusiveness of services, and others. It concludes with a list of lessons for family support based on these families' experiences.

TITLE: Parenting under pressure: Mothers and fathers with learning difficulties

AUTHORS: Booth, T., & Booth, W.

PUBLICATION INFORMATION: 1994

Buckingham: Open University Press.

Very little is known about the lives and the struggles of parents with learning difficulties. Parenting under pressure gives important insights into what it means to be a parent with a learning difficulty. Using a life story approach, the Booths produce personal accounts that give value to the so often ignored views of mothers and fathers. Life stories of half-a-dozen parents, both mothers and fathers, cover issues such as: parental fitness (disability and "good parenting" are not assumed incompatibilities), the price of support, effective and sensitive support, "ordinary living," community care,

rights and citizenship, good parenting, social justice, and discrimination. Readers are reminded that "a parent-child relationship based on love and affection is more easily supported than replaced."

TITLE: Supporting and strengthening families: Volume I - Methods, strategies and practices

AUTHORS: Dunst, C. J., Trivette, C. M., & Deal, A. G. (Eds.)

PUBLICATION INFORMATION: 1994

Cambridge, MA: Brookline Books.

This collection of papers updates the thinking on enabling and empowering families. "Empowerment implies that many competencies are already present or at least possible. Empowerment implies that what you see as poor functioning is the result of social structure and lack of functioning and a lack of resources which make it impossible for the existing competencies to operate. It implies that in those cases where new competencies need be learned, they are best learned in a context of living life rather than in artificial programs..." Issues discussed include: family support programs; individualized family support plans; family needs, strengths, and resources; and effective help-giving practices.

TITLE: Family support programs for families who have children with severe emotional, behavioral or mental disabilities: The state of the art

AUTHOR: Freud, E.

PUBLICATION INFORMATION: 1990

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

This monograph identifies and explores various approaches to supporting families having children with severe emotional disorders, a group that has traditionally been ignored in discussions of family support. Identifying the core components of family support as self-help, advocacy, parent education, respite care, family centered case management, and cash assistance, the monograph profiles nine programs in seven states. A discussion of the future of family support for this group of families concludes the monograph.

TITLE: Supporting families with a child with a disability: An international outlook

AUTHORS: Gartner, A., Lipsky, D. K., & Turnbull, A. P.

PUBLICATION INFORMATION: 1991

Baltimore: Paul H. Brookes Publishing Co.

This book examines family supports in nine countries, including the U.S., and brings together the areas of family, disability, and culture. It also touches briefly on issues of women and disability. The book begins by discussing how disability has been viewed in different cultures. It gives an overview of families with a child with a disability and has a strong parent versus professional focus. The book discusses basic social welfare and financial assistance, education, emotional support, employment, housing, and recreation in each of the nine countries.

TITLE: Functional life planning for persons with complex needs

AUTHOR: Green-McGowan, K.

PUBLICATION INFORMATION: 1987

KMG Corporation
P.O. Box 2534
Peachtree City, GA 30269

This manual covers a variety of areas: human anatomy and movement, functional assessment, principles of 24 hour planning, adaptive equipment, environmental modifications, establishing goals and objectives, principles of team planning, and individual services planning, among others. An extremely valuable resource for planning supports for people with complex medical needs.

TITLE: Assessment and planning for health professionals

AUTHORS: Green-McGowan, K., & Barks, L. S.

PUBLICATION INFORMATION: 1985

KMG Corporation
P.O. Box 2534
Peachtree City, GA 30269

The manual is an excellent resource covering such issues as the causes of health risk for people labelled as "medically fragile"; methods of collecting information including interviewing techniques and observation of the person; an evaluation schema for the neurological, musculoskeletal, respiratory, gastrointestinal/urinary, endocrine, behavioral and nutrition/eating systems; and information on the development of health improvement goals.

The assessment methodology was developed by KMG Corporation specifically for use with people labelled as "medically fragile" in order to identify and categorize their genuine level of health risk and to focus on the management methodology of improving those risks. The manual is written specifically for health professionals and has limited applicability for non-health professionals.

TITLE: The family as care manager: Home care coordination for medically fragile children

AUTHORS: Kaufman, J., & Lichtenstein, K. A.

PUBLICATION INFORMATION: 1986

Coordinating Center for Home and Community Care, Inc. (CCHCC)
P.O. Box 613, Severn Professional Building
Millersville, MD 21108

This workbook is an extremely valuable tool to assist parents and families in caring for their "medically fragile" child at home. Written clearly and concisely, it provides necessary and practical organizational information, as well as being an educational and informational resource tool.

Divided into four sections, Section I, the "Introduction," gives a brief review of what is entailed in a discharge plan, a very thorough needs assessment to be completed by the family, and a redefinition of "care manager." Section II, "Families as Care Managers," describes the five roles which families must assume as care managers: the role of medical manager, financial planner, educational advocate, resource specialist, and employer. Included within each topic are practical checklists and worksheets. Section III, "Maintenance of Records," explains the need for families to maintain an organized system of record keeping and delineates which information to include in an open file. Section IV, "Conversation with Families: Recurring Themes," lists those themes and concepts that the authors found to be common to families involved in home care for children with severe medical conditions.

TITLE: Come together: The experience of families with severe disabilities or chronic illness

AUTHOR: Knoll, J.

PUBLICATION INFORMATION: 1989

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

This report, prepared under a contract with SKIP of New York, is the story of 48 families in New York, widely diverse in terms of cultural, ethnic, religious, and economic backgrounds but having in common their children with severe disabilities or chronic illnesses. The report is based on a study conducted for two reasons: to understand the families' experience and to communicate that experience to policy makers and service providers, and to evaluate a case management and advocacy service provided to the families by Sick Kids (need) Involved People (SKIP) of New York, Inc. This resource is one of the few that report families' experience in such rich detail, and is a "must read" for people interested in services for these families.

TITLE: Family support services in the United States: An end of decade status report

AUTHORS: Knoll, J., Covert, S., Osuch, R., O'Connor, S., Agosta, J., & Blaney, B.

PUBLICATION INFORMATION: 1990

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

The first section of this document provides an historical context for family support, provides a synthesis of state family support efforts, and concludes by delineating some of the key issues surrounding the development of family support, including the need for supports which are family centered, culturally sensitive, community based, and well coordinated. The second section contains a description of family support activities in each state.

TITLE: Health care issues for children with special health needs and disabilities

AUTHORS: Lehr, S., & Taylor, S. J.

PUBLICATION INFORMATION: 1987

Technical Assistance for Parent Programs (TAPP)
Federation for Children with Special Needs
Suite 104, 95 Berkeley Street
Boston, MA 02116

This manual was developed as a resource for parents of children with special health needs or disabilities. The manual is designed to encourage parents to be the managers of their child's care and treatment, and to work collaboratively with health care practitioners for the benefit of the child. Section I outlines some of the key issues relating to the provision of health care and treatment for children with chronic illness and disabilities. Section II is a series of handouts that could be given to parents. Section III includes an overview of the Collaboration between Parents and Health Professionals (CAPP) Project and a reprint of the issue from Coalition Quarterly on health care issues. The last section refers the reader to additional resources.

TITLE: A license doesn't make you smart, or working with the "helping" professions

AUTHORS: McGowan, K. G., & McGowan, J. (Eds.)

PUBLICATION INFORMATION: 1993

SKIP of New York, Inc.
545 Madison Avenue, 13th Floor
New York, NY 10022

This is a manual for professionals who work with children with complex medical needs. It starts with assumptions that many professionals need to learn how to support children and families so that the children can live at home. It states specifically that attitudes shape behavior, and that many professionals receive very little training in the area of developmental disabilities. The authors look specifically at issues of adaptive equipment and obstacles that people may have to deal with, and show concrete ways to address these issues. In addition, there is a chapter on case management and how to provide services that let the individual control his or her environment. Finally, there is a long list of resources that includes books, other manuals, and vendors for all of the topics discussed.

TITLE: Down syndrome: Living and learning in the community

AUTHORS: Nadel, L., & Rosenthal, D. (Eds.)

PUBLICATION INFORMATION: 1995

Wiley-Liss, Inc.
605 Third Avenue
New York, NY 10158-0012

This edited book from the National Down Syndrome Society explores the community experiences of people with Down syndrome. It gives an overview of the latest medical advances which prolong lives of people with Down syndrome, provides information about programs and services, and provides personal accounts from young adults with Down syndrome. The book is divided into seven sections, with topics including parents' perspectives, family supports, language and cognitive development, behavior, education, health care advances, and independent living and other meaningful employment. The book's aim is to provide a tool for parents and health care professionals so they can better assist people with Down Syndrome to deal with any problems they may face and to participate to the fullest extent in community life.

TITLE: Michigan Department of Mental Health report on Family Support Subsidy Program FY 85-86

AUTHORS: Parrott, M. E., & Herman, S. E.

PUBLICATION INFORMATION: 1987

Michigan Department of Mental Health
Lewis Cass Building
Lansing, MI 48926

This paper describes Michigan's family support subsidy program in detail. The subsidy is one piece of an overall policy of family preservation which includes family supports and permanency planning. Permanency planning is the philosophy which provides the framework for service delivery. The underlying assumption in permanency planning is that children need parents, a home, and other family members with whom to interact. The subsidy provides financial support to families who have children with severe handicaps. It currently serves 2,700 families. The report provides results of an evaluation of the program. These results indicate that families have found the program helpful in meeting the special needs of their child and the family as a whole and that community mental health boards noted few problems in identifying

eligible children. The program has been successful in averting some out-of-home placements and has been a factor in the return home of some children. For those children who have been placed out-of-home, the Department's policy of permanency planning is resulting in efforts toward reunification of families or the establishment of alternative permanent homes for children.

TITLE: Mealtimes for severely and profoundly handicapped persons: New concepts and attitudes

AUTHORS: Perske, R., Clifton, A., McLean, B. M., & Stein, J. I.

PUBLICATION INFORMATION: 1986

Baltimore: Paul H. Brookes Publishing Co.

The term Mealtimes is an apt title for this marvelously written and useful book. This book does not simply describe proper "feeding" techniques for people with severe and multiple disabilities. It shows how mealtimes can be designed to be pleasant and enjoyable experiences.

Sensitively written and superbly edited, this book is a collection of articles by professionals, parents, people with disabilities, administrators, and others. The book starts out with an introduction written by Robert Perske entitled, "A Gentle Call to Revolution." Perske sets the tone for the book in this introductory chapter by stressing the need for "dignity, kindness, cooperation, and skill." The remainder of the book is divided into four sections: Value of Mealtimes, Creative Interactions, Creative Uses of People, and Helpful Settings.

This is not intended to be a how-to-do-it handbook. Instead, the purpose is "to allow a wide range of people to speak plainly about the fresh attitudes they have developed about mealtimes and the innovative things they are trying to do."

Anyone who works with people with severe and multiple disabilities should read this book. Parents, caregivers, and agency administrators will find it especially useful.

TITLE: Your child and health care: A "dollars & sense" guide for families with special needs

AUTHOR: Rosenfield, L. R.

PUBLICATION INFORMATION: 1994

Baltimore: Paul H. Brookes Publishing Co.

This is a comprehensive and easy to read book for families of children with disabilities or chronic health care needs, and for professionals to utilize too. This how-to guide starts with the rights of parents and their children, with references to relevant legislation and court cases. It gives a wealth of information on the federal and state level, and gives sources of financial assistance, including federal assistance such as SSI and AFDC. There is also an extensive glossary for the numerous terms used throughout the book (and that professionals use exclusively) and a bibliography for further reading.

TITLE: "Like an angel that came to help us": The origins and workings of New Hampshire's family support network

AUTHOR: Shoultz, B.

PUBLICATION INFORMATION: 1993

Syracuse, NY: Center on Human Policy, Syracuse University.

This report reviews the history of family activism in New Hampshire, the activities of the legislative Task Force on Family Support, and the establishment of a Family Support Network consisting of a Family Support Council in each of New Hampshire's twelve regions for serving people with developmental disabilities. This report also describes the workings of the Councils and the Network, raises issues for discussion, and concludes with lessons to be drawn and implications for other states. It is based on document review, and in-depth interviews with key players.

TITLE: Support for caregiving families: Enabling positive adaptation to disability

AUTHORS: Singer, G. H. S., & Irvin, L. K. (Eds.)

PUBLICATION INFORMATION: 1989

Baltimore: Paul H. Brookes Publishing Co.

This edited book covers a broad range of issues related to supporting families. Chapters include discussions of family strengths, value-based services, coping skills, informal social support, and various kinds of formal support such as respite care, cash assistance, early intervention, counseling, and many other formally arranged supports. The final chapters have to do with evaluation and policy development.

TITLE: Redefining family support: Innovations in public-private partnerships

AUTHORS: Singer, L. E., Powers, L. E. , & Olson, A. L.

PUBLICATION INFORMATION: 1996

Baltimore: Paul H. Brookes Publishing Co.

"Families need comprehensive and flexible support to enable them to lead balanced lives while meeting the needs of a family member who has a disability." In recognition of this need, states are increasingly, but slowly, implementing more family-centered approaches in the design and implementation of supports to individuals with special needs and their families. Redefining family supports is one in a series of books whose purpose is to provide a forum for contemporary work on the challenges and issues that families face and various effective ways of supporting families with a member with a disability. In this particular book, the focus is on innovations and public-private partnerships in family supports. Specific topics include: trends affecting home and community care for people with chronic conditions, development of standards and measurement of practice in family supports programs, family empowerment, primary prevention, the aging family from a multigenerational perspective, early intervention, family support in cases of neglect and abuse, family support in child and adult mental health, the role of education in community supports, and family and consumer activism.

TITLE: Families to families: An introduction to the home care experience

AUTHORS: SKIP of Maryland, Inc. & SKIP National

PUBLICATION INFORMATION: 1988

SKIP National
500 East 83rd Street, Suite # 1B
New York, NY 10028

Sick Kids (need) Involved People (SKIP), a national organization of parents and professionals involved in home care for children with complex medical needs (often including dependence on medical equipment like ventilators or apnea monitors), has produced this manual for parents. There are chapters on thoughts and feelings, dealing with the hospital, discharge planning, common problems, community integration, and references to resources. This is an excellent resource for families and caring staff persons.

TITLE: "Children's Division is coming to take pictures": Family life and parenting in a family with disabilities

AUTHOR: Taylor, S. J.

PUBLICATION INFORMATION: 1995

In S. J. Taylor, R. Bogdan, & Z. M. Lutfiyya (Eds.), The variety of community experiences: Qualitative studies of family and community life (pp. 23-45). Baltimore: Paul H. Brookes Publishing Co.

"Children's division is coming to take pictures" tells the story of the Duke family. The outside world views the Dukes in terms of mental retardation, physical disabilities, seizures, emotional, and mental disorders; a family in which both the parents and the children have mental retardation. The Dukes, on the other hand, see themselves as loving, caring parents who have worked hard to advocate for, and support, their children. Resourceful people, the Dukes believe strongly in kin supporting and helping one another as a means of coping with their marginal economic and social status.

Using the Dukes as his focus, Taylor discusses parenting issues related to parents with disabilities, and concludes with a number of important lessons for human service providers, including: how best to provide support, what types of supports may be useful, and thoughts on when and where to intervene on the behalf of children.

TITLE: Community living in three Wisconsin counties

AUTHOR: Taylor, S. J.

PUBLICATION INFORMATION: 1991

In S. J. Taylor, R. Bogdan, & J. A. Racino (Eds.), Life in the community: Case studies of organizations supporting people with disabilities (pp. 55-70). Baltimore: Paul H. Brookes Publishing Co.

Wisconsin has a history of innovation in support services for children and adults with developmental disabilities. This chapter examines examples of this innovation within three counties, Dane, LaCrosse, and Columbia. It describes aspects of county leadership that promote community integration for people with severe disabilities; case management practices that support integration; and family support strategies.

TITLE: Towards families for all children

AUTHOR: Taylor, S. J.

PUBLICATION INFORMATION: 1991

In S. J. Taylor, R. Bogdan, & J. A. Racino (Eds.), Life in the community: Case studies of organizations supporting people with disabilities (pp. 19-34). Baltimore: Paul H. Brookes Publishing Co.

Michigan has a reputation as a national leader in the depopulation of institutions for people with developmental disabilities and the support of children and their families. This has been the result of a combination of factors. This chapter examines some of these factors. It begins by reviewing the Michigan Family Subsidy Act, which provides cash subsidies to families of children with severe disabilities. The author then discusses the philosophy of permanency planning, which has been key to designing supports for children to live with families. Next, the chapter provides some background information on community mental health programs in the state. Within the state, the Macomb-Oakland Region has been exceptional in its efforts toward deinstitutionalization and support of families. The chapter concludes with a detailed description of some aspects of this region's success, including the leadership and commitment, as well as the support for foster families for children with severe and multiple disabilities who are not living with natural or adoptive families.

TITLE: A mother's work is never done: Constructing a "normal" family life

AUTHOR: Traustadottir, R.

PUBLICATION INFORMATION:

In S. J. Taylor, R. Bogdan, & Z. M. Lutfiyya (Eds.), The variety of community experiences: Qualitative studies of family and community life (pp. 47-65). Baltimore: Paul H. Brookes Publishing Co.

Like any other family, families of children with disabilities also try to "lead ordinary lives." Past studies of how these families construct "normal" lives have been based on a traditional view of the mother within the family. Here, mothers' "naturalness" in constructing "normal" lives in the face of deviance, is not taken for granted. Rather, this study analyzes the "gendered organization of the work of constructing and maintaining a normal family life." Drawing on the results of in-depth interviews with 26 mothers and 5 fathers of children with disabilities, Traustadottir

considers the themes of: being part of the family; parents' conception of ordinary family life; disability and the construction of gender; disability service issues; family image; and class, race, and family life.

TITLE: Technology and children with disabilities: A guide for family members

AUTHOR: Turnbull, H. R.

PUBLICATION INFORMATION: 1989

Beach Center on Families and Disability
Bureau of Child Research
4138 Haworth Hall
Lawrence, KS 66045

This booklet describes two federal laws in lay terms: P.L. 100-407, the Technology-Related Assistance for Individuals with Disabilities Act of 1988, and P.L. 100-360, the Medicare Catastrophic Coverage Act of 1988 (repealed late in 1989).

TITLE: Family support bulletin

AUTHOR: United Cerebral Palsy Associations

PUBLICATION INFORMATION:

UCPA Governmental Activities Office
1522 K Street N.W., Suite 1112
Washington, DC 20005

The Family support bulletin published its first issue in Summer 1987. Its threefold purpose is: (1) to be a source of information, research, policy and practice regarding supports for families having children with severe disabilities; (2) to solicit comments, articles, successes, and failures in family support services; and (3) to develop a national network of people committed to assuring the development of consistent policies in the private and public sector supporting families.

TITLE: Technology-dependent children: Hospital vs. home care--A technical memorandum

AUTHOR: U.S. Congress, Office of Technology Assessment

PUBLICATION INFORMATION: 1987

U.S. Government Printing Office
Washington, DC 20402-9325
(GPO # 052-003-01065-8)

This report is an effort to provide Congress with the data necessary to examine issues surrounding care for the increasing number of children who are in need of on-going nursing care or medical technology in order to survive. It begins by looking at various definitions of this population and discussing how the definition affects any efforts to project long-term need for services. It offers a definition and then makes projections based on that definition. The next section examines the comparative effectiveness and cost of hospital versus home-based care. The general conclusion here is that home care can be as effective in the medical-technical realm as hospital care of most conditions and it tends to be more cost effective. However a number of potential problems inherent in "pushing" home care (e.g., placing unrealistic demands on families who are not up to them) are highlighted. The final section discusses sources of financing for home based care. There are major discussions of private insurance and a great deal of information on the range of Medicaid waiver programs (at the time data was collected in mid-1986). There are also sections dealing with other programs which pay for home care. This report is essential reading for anyone who wishes to be informed on this issue.

TITLE: Family supports for children with severe disabilities and chronic illnesses

AUTHOR: Walker, P.

PUBLICATION INFORMATION: 1991

In S. J. Taylor, R. Bogdan, J. A. Racino (Eds.), Life in the community: Case studies of organizations supporting people with disabilities (pp. 71-81). Baltimore: Paul H. Brookes Publishing Co.

This chapter focuses on some of the positive family support practices in Maryland, especially for families whose children have severe disabilities and chronic illnesses. The chapter begins with an overview of three agencies. It then describes some aspects of individualized and flexible supports for children and families,

including those related to medical needs as well as personal support. The chapter also discusses strengths associated with using a team approach to family support, the idea of "service coordination" versus case management with the connotation of "managing" families, and issues related to advocacy and empowerment.

TITLE: Family support program: Guidelines and procedures

AUTHOR: Wisconsin Department of Health and Social Services

PUBLICATION INFORMATION: 1985

Wisconsin Department of Health and Social Services
One West Wilson Street
P.O. Box 7851
Madison, WI 53707

This report gives a detailed description of Wisconsin's family support program, including: an overview (purpose, available services, etc.) of the program; the development of individualized family service plans; and administration of the program. Appendices include family support legislation, as well as samples of various program forms (i.e., family questionnaire, application for services, etc.).

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2. Permanency Planning

The materials in this subsection discuss the concept of permanency planning for children with developmental disabilities, from the point of view that all children need a permanent family. Permanency planning strategies include a "whatever it takes" approach to family support, family reunification efforts, and adoption or permanent foster care for children who cannot return to live with their birth families. For additional information on permanency planning, see two articles annotated in the previous section: Parrott & Herman (1987) and Taylor (1991).

TITLE: Parents for children, children for parents: The adoption alternative

AUTHOR: Glidden, L. M.

PUBLICATION INFORMATION: 1989

American Association on Mental Retardation (AAMR)
444 North Capitol Street, NW, Suite 846
Washington, DC 20001-1570

This book is based on interviews with families into which children with developmental disabilities have been adopted and with agency workers responsible for arranging such adoptions. The book is organized to follow the steps in the birth and adoption process, giving many facts and statistics in each chapter. This is a good resource for agencies thinking about providing for adoption for children with disabilities.

TITLE: Permanency planning practice for children with developmental disabilities within the Michigan mental health system: A manual for trainers

AUTHOR: Michigan Department of Mental Health in cooperation with Spaulding for Children

PUBLICATION INFORMATION: 1987

Community Services
Michigan Department of Mental Health
Lewis Cass Building
Lansing, MI 48926

This training manual is designed to build commitment by staff of mental health and developmental disabilities agencies to the philosophy of permanency for children with developmental disabilities. This philosophy includes a commitment to maintaining children in families, whether birth or alternative families, in order that the child may have permanent ties and relationships. The manual is divided into ten units, with each unit serving as the basis for a training session of one-half to one day in length. The units include: 1) Preparing to train; 2) Gaining administrative and managerial support; 3) Permanency planning: What? Why? How?; 4) The bonding experience; 5) Aggressive, decisive case management; 6) Developmental assessment and preparation; 7) Family assessment in the mental health system; 8) Preservation and reunification practice; 9) Adoption of children with developmental disabilities; 10) Lifespan advocacy. This is an excellent resource for anyone interested in children.

TITLE: Annotated bibliography: Permanency planning (P.L. 96-272)

AUTHORS: Petr, C. G., Zollars-White, J., Garlow, J., Turnbull, H. R., III, & Roessier, J. A.

PUBLICATION INFORMATION: 1990

Beach Center on Families and Disability
Department of Special Education and
Bureau of Child Research
The University of Kansas
3111 Haworth Hall
Lawrence, KS 66045-0048

There are three parts to this annotated bibliography on permanency planning: (1) an annotated outline of background and issues related to P.L. 96-272, The Adoption Assistance and Child Welfare Act of 1980; (2) annotation of articles related to adoption of children with special needs; and (3) a broader listing of additional resources related to permanency planning and adoption.

TITLE: Permanency planning in Michigan: From philosophy to reality

AUTHORS: Shoultz, B., O'Connor, S., Hulgin, K., & Newman, P.

PUBLICATION INFORMATION: 1994

Syracuse, NY: Center on Human Policy, Syracuse University.

This report begins with an overview of the permanency planning philosophy and a description of permanency planning services in the developmental disabilities system and mental health system in Michigan. Based on interviews with families, the report then discusses families' experiences with the implementation of permanency planning services and related issues and challenges for service providers.

TITLE: Permanency planning for children with developmental disabilities in Pennsylvania: The lessons of Project STAR

AUTHORS: Taylor, S. J., Racino, J. A., Walker, P., Lutfiyya, Z. M., & Shoultz, B.

PUBLICATION INFORMATION: 1992

Syracuse, NY: Center on Human Policy, Syracuse University.

This report examines the lessons for state and county policy on "permanency planning" and "special needs adoption" for children with disabilities based on the experience of Project STAR in Pittsburgh, Pennsylvania. It is divided into three major parts. Part I reviews the history and experience of Project STAR. Part II examines the policy context in which Project Star operates. Part III addressees policy issues that have an impact on Project STAR's mission and contains policy recommendations based on this review.

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3. Community Living for Adults

The emerging approach to "community living" for adults with disabilities may be called an "individualized," "person-centered" or "housing/support strategy" approach. Essentially, this approach looks at housing and support as basic needs that people have. This approach reflects the tradition of packing housing and support together along a continuum of residential services. The most important part of a housing/support approach is to start with the person and his or her preferences for how, where, and with whom he or she would like to live. This means a person would (1) have individually tailored and flexible supports available wherever he or she chooses to live; (2) have the option to rent or own his or her own home; and (3) have choices in all aspects of life from major decisions, such as the location of the home, to more minor decisions such as scheduling staff time. This approach to housing and support services, of course, needs to be embedded in the broader context of community, family, relationships, and so forth. For resources in this area, please see the other bibliography sections, such as those in the "Beyond Paid Services and Supports" division of this bibliography and those in the "Planning and Developing Supports with Individuals" section.

The subsections below contain materials that discuss housing and support for community living as well as some materials more specifically oriented toward housing issues.

a. Support Issues

TITLE: Community living for adults

AUTHOR: Center on Human Policy

PUBLICATION INFORMATION: 1989

Syracuse, NY: Center on Human Policy, Syracuse University.

This newsbulletin presents and summarizes some concepts related to supported living. It includes stories which describe the lives of a number of individuals who are living in their own homes and apartments and gives an overview of several agencies that have adopted an individualized approach to services. Though much has changed in the area of supported living since the development of this bulletin, its contents are still relevant.

TITLE: Self-directed attendant services: Toward a consumer oriented policy and perspective on personal support services

AUTHOR: Centre for Research and Education in Human Services

PUBLICATION INFORMATION: 1990

Centre for Research and Education in Human Services
P.O. Box 3036, Station C
Kitchener, ON N2G 4R5
CANADA

For U.S. readers, the most interesting parts of this monograph are its analysis of the difference between a health/welfare model and a rights/empowerment model for provision of personal support for people with physical disabilities, and the framework it presents for self-directed attendant services. The approach the monograph espouses is based on a qualitative study of consumers' wishes and desires, and is most applicable for people who do not need support to direct their own attendants. Many of the ideas proposed, however, could be adapted to meet the needs of people who do need such support--for example, a rights/empowerment approach rather than an approach that removes choice and control from the person.

TITLE: Innovation in the way people with disabilities can be supported to live and participate in community life

AUTHOR: Chernets, G.

PUBLICATION INFORMATION: 1995

In L. Nadel & D. Rosenthal (Eds.), Down syndrome: Living and learning in the community (pp. 256-262). New York: Wiley-Liss, Inc.

This chapter, written by a parent of three daughters, two of whom have disability labels, describes the development of two housing cooperatives and a support organization which works in conjunction with the cooperatives to support members with disabilities. The coops--Courtyard and CHORD--are committed to the creation of welcoming, inclusive, supportive communities composed of people of various ages, income levels, abilities, and cultural origins. The support organization, NABORS, works in conjunction with the coop communities. In addition to describing the philosophy and organizational structure of the coops and NABORS, the author discusses some of the experiences of her daughter, Kerrie, within the coop.

TITLE: Jay Nolan Community Services: The advantages and dilemmas of converting quickly from group homes to supported living services

AUTHOR: Hulgin, K.

PUBLICATION INFORMATION: 1996

Syracuse, NY: Center on Human Policy, Syracuse University.

Jay Nolan Community Services is a nonprofit organization that provides a range of services to people with autism and other developmental disabilities in Los Angeles, California. Since January 1993, this agency has made remarkable changes in the way that it provides residential services. It has moved from operating group homes to supporting people to live in their own homes. This report, based on a visit in November 1995, describes this process of change.

The first section outlines the agency process of transition from group homes to supporting people in their own homes. This section includes a discussion of significant opportunities and strategies that contributed to the agency's success in this relatively quick change process, including: (1) learning from other agencies that had been successful in developing supported living services; (2) culturing the commitment and skills of a team of staff; (3) clarifying issues related to decision making power; (4) giving families opportunities to learn about supported living; and (5) agreeing to shift to supported living services without asking for increased state funding.

The following section describes ways in which the agency has begun to identify and respond to the needs and preferences of individuals over the long term, including: implementing circles of support; rearranging staff responsibilities; providing continuous opportunities for learning; and working to gain system support. Another section describes some specific changes that have occurred in a few people's lives. And, the report ends with a summary of lessons that have emerged from implementing a supported living approach in this agency.

TITLE: Belonging to the community

AUTHOR: Johnson, T. Z.

PUBLICATION INFORMATION: 1985

Options in Community Living
22 North Second Street
Madison, WI 53704

This book is a valuable resource for the residential provider concerned with providing supportive living services to people with severe disabilities. It is made up of a series of six papers which describe Options in Community Living, a supported apartment program in Madison, Wisconsin.

The six sections of the manual include: 1) an overview of the Options program, with particular emphasis on the values which guide it and how it has changed over time; 2) a description of this agency's administrative structure, including the definitions of various administrators' roles, funding considerations, and consumer participation; 3) a review of Options' staff organization with clear descriptions of its team approach, various staff positions (including overviews of a typical day in the life of various staff members), and procedures for staff hiring, training, and evaluation; 4) an examination of the fundamental principles which guide this agency's service practice and a review of the processes used to plan, implement, and evaluate activities on behalf of each individual served by it; 5) a discussion of how an agency can aid someone's integration into the community with special attention given to major dilemmas, strategies, issues of relationship building, and advocacy for change in the community; and 6) an analysis of how services are adapted to meet the needs of "special populations," including people with physical disabilities, people with significant learning problems, and people with challenging behaviors. Each paper is supplemented with a variety of useful materials which rum the gamut from maps and budgets to job descriptions, assessment forms, and policy statements.

The entire manual is useful, but the final three sections provide instructive, thought provoking reading for anyone involved in supporting people with severe disabilities in the community. It is particularly refreshing to find a resource which directly recognizes the difficult issues of autonomy, choice, risk, and relationship building which emerge when an agency is truly committed to facilitating the integration of individuals into the community.

TITLE: Carrying Options' story forward: Final report of an assessment of Options in Community Living

AUTHORS: Johnson, T., & O'Brien, J.

PUBLICATION INFORMATION: 1987

Options in Community Living, Inc.
22 North Second Street
Madison, WI 53704

An excellent supplement to the Options manual, this evaluation report focuses on the views of Options staff on a variety of topics, ranging from their descriptions of the people they serve to issues they see as pertinent to future development. The report also includes feedback by the evaluators on issues pertinent to the staff and of concern

to most service providers, such as the amount of involvement staff have in people's lives and how to help people develop relationships with community members. Staff concerns regarding the amount of time they had to devote to assist in building relationships along with the inadequacies they felt in being responsible for "getting friends for people" are also presented. The report provides some constructive ways in which staff might enhance the building of relationships, and describes Options' continued commitment in principle and action to supporting people with severe disabilities.

TITLE: Case studies of six state personal assistance service programs funded by the Medicaid personal care option

AUTHORS: Kennedy, J., & Litvak, S.

PUBLICATION INFORMATION: 1991

World Institute on Disability
510 16th Street, Suite 100
Oakland, CA 94612-1502

This report provides case studies of six state personal assistance service programs funded by the Medicaid personal care option. The programs studied provided a wide variety of services to both people with disabilities and their family members, across the country. Each case study includes an overview of the program, a history of the program, gate keeping and supervision functions, service limits, available support services, a discussion of attendant issues, the context of the program (who is/is not served, who "falls through the cracks"), and views of the individuals interviewed on site.

TITLE: Get me the hell out of here: Supporting people with disabilities to live in their own homes

AUTHOR: Klein, J.

PUBLICATION INFORMATION: 1992

In J. Nisbet (Ed.), Natural supports in school, at work, and in the community for people with severe disabilities (pp. 277-339). Baltimore: Paul H. Brookes Publishing Co.

Through a compilation of personal stories, this chapter describes the provision of community supports for adults with developmental disabilities developed by a residential support program in Greeley, Colorado. The first section outlines Jeanne's story of transition from an institution to her own home. Next, a brief historical background of the evolution of residential services is provided, as well as a discussion of this program's transition from providing residential services to residential supports. The fourth section contains Karren's story as further illustration of various supports. This is followed by a section which proposes a set of values for residential support. The sixth section outlines the process for developing residential supports, using Sharon's story as an example. Finally, the chapter concludes with an examination of what has been learned from this approach to providing supports and implications for future directions.

TITLE: IMPACT: Feature issue on supported living

AUTHORS: Lakin, K. C., & Smull, M. (Eds.)

PUBLICATION INFORMATION: 1995

Minneapolis: Institute on Community Integration, University of Minnesota.

In this issue of IMPACT, leaders in the development of supported living describe the challenges, issues, and accomplishments of this movement. Articles describe projects and efforts at the national, state, agency, and individual level. Also included are resources related to these efforts.

TITLE: A checklist for evaluating personal assistance services (PAS) policies and programs

AUTHORS: Lyle O'Brien, C., & O'Brien, J.

PUBLICATION INFORMATION: 1992

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

This checklist was compiled in conjunction with individuals from a number of advocacy and activist groups for persons with disabilities. The list will help individuals evaluate personal assistance services (PAS) by breaking down the three broader areas of availability, comprehensiveness, and controllability.

TITLE: Personal assistance services for persons with mental disabilities

AUTHOR: Nosek, M. A.

PUBLICATION INFORMATION: 1990

Baylor College of Medicine
3400 Bissonet, #101
Houston, TX 77005

This paper, prepared for the National Council on Disability, provides an excellent review of the developmental disabilities and mental health literature on personal assistance services, including both formal and informal support. The paper concludes that "the principle of individuals determining and maintaining a life style of their choice has emerged as a common thread across recent developments in all disability groups" (p. 8). It points out the challenge of changing the traditional service systems and funding mechanisms to allow this principle to be realized, and asks that policy makers develop policy strategies that will make this possible.

TITLE: Supported living: What's the difference?

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1993

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

In this article O'Brien distinguishes between supported living and other service approaches. He argues that understanding supported living requires a reconsideration of assumptions and behavior toward people with disabilities. The article begins with descriptions by service providers, who have pioneered the approach, of experiences which have enabled them to step outside the assumptions and practices that usually govern service providers. This is followed by the identification of issues that should govern supported living services and a concluding list of the obligations of service providers to individuals and their friends and families.

TITLE: Living with the questions: Notes from a gathering of people concerned with supported living

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1995

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

This report was generated from a gathering of innovators in the supported living movement including: people with disabilities, family members, service providers, and system managers. Participants in the gathering drew upon their experiences to describe issues related to supporting people to live in their communities. Their experiences provide an in-depth understanding of this process. Topics include contradictions with system rules, how support makes a difference in people's lives, concerns in the day to day work of service providers, and strategies for growth of supported living. The report ends with reflections by several participants.

TITLE: Settling down: Creating personal supports for people who rely on the residential support program of Centennial Developmental Services

AUTHOR: O'Brien, J., & Lyle, C.

PUBLICATION INFORMATION: 1989

Responsive Systems Associates
58 Willowick Drive
Lithonia, GA 30038

This is a report on one organization that began a process in 1985 of transforming the way that people with developmental disabilities live in Weld County, Colorado. In addition to describing the transformation process, this report highlights leadership, the dimensions of the relationship between staff and each individual they support, moving to a deeper understanding of choice for people with severe disabilities, changes in staff roles, among a myriad of other issues.

TITLE: From behind the piano: The building of Judith Snow's unique circle of friends

AUTHOR: Pearpoint, J.

PUBLICATION INFORMATION: 1990

Inclusion Press
24 Thome Crescent
Toronto, ON M6H 2S5
CANADA

This small book tells the story of Judith Snow and her Circle of Friends, the Joshua Committee. This powerful personal account details the combined efforts of Judith and the Joshua Committee as they worked to free her from a hospital ward and pull together community supports. It also describes the ongoing collaboration to support Judith in the community. In doing so, it addresses fundamental issues related to community support, such as funding, personal care attendants, and relationships and social networks.

TITLE: Housing, support, and community: Choices and strategies for adults with disabilities

AUTHORS: Racino, J. A., Walker, P., O'Connor, S., & Taylor, S. J. (Eds.)

PUBLICATION INFORMATION: 1993

Baltimore: Paul H. Brookes Publishing Co.

This book provides an in-depth look at and analysis of the issues related to supporting adults with disabilities to live in their own homes. It is divided into three parts. In Part I, several chapters address the complexities of a housing and support approach compared with traditional approaches. Issues discussed here include the importance of separating housing and support, choice and decision-making, support versus supervision, and changing roles of organizations.

Parts II and II of this book provide personal and organizational perspectives related to housing and support efforts. Part II consists of four essays, including one by a parent, one by a person who has provided personal care attendant services, and two by individuals with disabilities, which provide first hand accounts of the challenges and opportunities afforded by a housing and support approach. The last part of this book contains five case studies of organizations that have implemented the concepts and principles discussed in Part I.

TITLE: Regenerating a community: The story of Residential Inc.

AUTHOR: Shoultz, B.

PUBLICATION INFORMATION: 1993

In J. A. Racino, P. Walker, S. O'Connor, & S. J. Taylor (Eds.), Housing, support, and community: Choices and strategies for adults with disabilities (pp. 281-298). Baltimore: Paul H. Brookes Publishing Co.

This chapter is a case study of Residential, Inc., a small agency in rural Ohio that has reorganized its services from operating group homes to assisting people to live in homes of their own. The study describes some of the dilemmas they faced and strategies they developed in creating housing opportunities, including changing staff roles and developing better problem solving strategies. Their work eventually evolved into the effort to build a strong community and led them to develop the Perry County Housing Association which is also described in the chapter.

TITLE: Life in the community: Case studies of organizations supporting people with disabilities

AUTHORS: Taylor, S.J., Bogdan, R., & Racino, J.A. (Eds.)

PUBLICATION INFORMATION: 1991

Baltimore: Paul H. Brookes Publishing Co.

This book is a collection of case studies of organizations supporting people with disabilities. The case studies are based on site visits utilizing qualitative research methods. They are part of a study focused on identifying positive examples of agencies providing individualized supports. Several of the case studies focus on supports for adults. The editors conclude with a chapter summarizing some of the key characteristics of responsive organizations, including: shared values, openness to change, committed and caring leadership, and sensitivity to social issues.

TITLE: Supports for community living: A case study

AUTHOR: Traustadottir, R.

PUBLICATION INFORMATION: 1991

Syracuse, NY: Center on Human Policy, Syracuse University.

This report is based on a qualitative study which examines in detail the supports provided to one individual with severe disabilities and the role of this support in enabling him to become part of community life.

TITLE: A step-by-step guide to training and managing personal attendants
Volume 1: Consumer guide
Volume 2: Agency guide

AUTHORS: Ulicny, G. R., Adler, A. B., et al.

PUBLICATION INFORMATION: 1987

Research and Training Center
on Independent Living (RTC/IL)
University of Kansas
Lawrence, KS 66045

These step-by-step instruction manuals are detailed guides for consumers and agencies who are exploring the usage and employment of personal care attendants (PCAs). These manuals begin with a discussion of pre-employment preparation. Practice interviews are encouraged and a thorough analysis of one's needs before beginning the recruitment process is stressed as a necessity. A look at matching applicant characteristics and personal needs and expectations follows. The manuals also contain detailed guides to assist consumers with providing appropriate feedback to their PCAs. Scheduling and emergency back-up networks are included topics.

Both of these manuals are styled in an easy-to-read and friendly format. The first manual is written for the consumer and was developed by a group of people experiencing disabilities. The second manual, which is an agency guide, focuses on enabling the consumer to regulate the use of their PCAs, as much as possible, while providing back-up support to ensure that quality standards are being met. The agency manual is an addendum to the consumer guide.

TITLE: Not just a place to live: Building community in Toronto

AUTHOR: Walker, P.

PUBLICATION INFORMATION: 1997

Syracuse, NY: Center on Human Policy, Syracuse University.

While many people with disabilities now live in housing cooperatives, this alone does not necessarily mean that they are part of the coop community. This case study describes the intentional creation of two inclusive housing cooperatives by a group of people with and without disabilities. Additionally, this effort involved the formation of NABORS, an organization designed to support the participation of coop members with disabilities. The report describes various aspects of coop formation, such as the Board structure, mission and values, membership issues, and funding issues. It also describes ideas and strategies to promote social inclusion, not just physical inclusion.

TITLE: Standing in support, not control: Training Toward Self-Reliance, Sacramento, CA

AUTHOR: Walker, P.

PUBLICATION INFORMATION: 1997

Syracuse, NY: Center on Human Policy, Syracuse University.

This is a case study of Training Toward Self-Reliance, an agency in Sacramento, California. It describes the agency's support of people with developmental disabilities, in particular: (1) support for parents who have disabilities; (2) support for people with developmental disabilities to manage their own personal care attendant services; and (3) support for people who experience multiple social problems and difficulties in addition to disability (e.g., homelessness, poverty, abuse). This report describes some of the lessons learned by agency staff as well as changes they have made, over time, in order to better support people, in individualized ways, to be a part of their community.

TITLE: Personal perspectives on personal assistance services

AUTHORS: Weissman, J., Kennedy, J., & Litvak, S. (Eds.)

PUBLICATION INFORMATION: 1992

World Institute on Disability
510 Sixteenth Street, Suite 100
Oakland, CA 94612-1500

The World Institute has been studying Personal Assistance Services (PAS) for the past decade. This document stems from the responses of the representatives from over 40 states and 10 countries who were in attendance at a 1991 World Institute on Disability symposium on PAS. The essays which comprise this manuscript represent a wide range of experience with PAS as it relates to many different types of disabilities

and life situations. Responses included reflections on PAS from the following perspectives: personal and political, the family, the benefits of PAS, the effect of PAS on family relationships, PAS for people labeled with mental retardation, what teens think about PAS, gay and lesbians issues, a multicultural perspective, PAS and people with a head injury, PAS and AIDS, and PAS and people who use a respirator.

TITLE: Personal assistance services: A guide to policy and action (2nd ed.)

AUTHOR: World Institute on Disability

PUBLICATION INFORMATION: 1992

World Institute on Disability
510 Sixteenth Street, Suite 100
Oakland, CA 94612-1500

This comprehensive loose leaf guidebook provides a wealth of information for a variety of people on personal assistance services. A definition of personal assistance service is provided, as are the current policy issues in the field. There are four major sections, and the book includes details from prior research conducted by the World Institute on Disability, published articles, and suggestions for change. After the introduction, the first section describes the current personal assistance services system, including a description of the type of people who receive these services. The section also includes state and federal funding sources, as well as a copy of an article on the issue of consumer choice. The next section includes drafts of federal legislation on funding and provision of services, as well as an article from an ADAPT newsletter, which advocates for attendant programs. An additional chapter in the book looks at innovative models for providing personal assistant services, and steps to make these services happen. In addition, there is an article on personal assistance in Sweden, where national policies support the needs of all people to live in the community. The book closes with a glossary and publications that advocates may find useful.

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b. Housing

The resources in this section deal with a variety of creative options that can be used to purchase or subsidize rents for ordinary (rather than segregated or specialized) housing in the community, including apartments, houses, condominiums, and housing cooperatives. Some information is included on adapting or building housing to meet the needs of people with physical disabilities.

TITLE: A survey of housing trust funds
and
A guide to developing a housing trust fund

AUTHOR: Center for Community Change

PUBLICATION INFORMATION: 1989, January

Center for Community Change
1000 Wisconsin Avenue, N.W.
Washington, DC 20007

The first of these two 100-page manuals offers an overview of housing trust funds describing how they work, what they have done, where they exist, and who to contact for further information. It also includes profiles of housing trusts in 34 states. The second book presents a guide to developing housing trust funds. Here the reader is given an overview, principles for developing housing trust funds, different models of administration, revenue sources and information on program issues (e.g., eligibility). Both books provide a bibliography for further reference.

TITLE: Cooperative housing: People helping each other

AUTHORS: Cooperative Housing Foundation and National Association of Housing Cooperatives

PUBLICATION INFORMATION:

Cooperative Housing Foundation
1010 Wayne Avenue, Suite 240
Silver Spring, MD 20910

National Association of Housing Cooperatives
1612 King Street
Alexandria, VA 22314

Cooperative housing is a short book offering the reader basic information on housing cooperatives, including a brief history of their development, information on who might be interested in living in a coop, how a coop is structured and how to get started. The finances of coop establishment are presented including members' costs and issues in start-up. Finally, the book offers a comparison of rental, individual ownership and cooperative living, including such areas as ownership, community control, management, and tax benefits.

TITLE: Guidebook on consumer controlled housing

AUTHORS: Field, T., & Lakin, K. C.

PUBLICATION INFORMATION: 1995

Minneapolis: Institute on Community Integration, University of Minnesota.

This guidebook outlines basic principles, considerations, and service strategies in choosing and securing consumer controlled housing for persons with developmental disabilities. It also includes information on assessing the need for and obtaining home modification planning for long-term supports and source of assistance.

TITLE: Working with non-profit developers of affordable housing to provide integrated housing options for people with disabilities

AUTHOR: Housing Technical Assistance Project

PUBLICATION INFORMATION: 1989

Housing Technical Assistance Project (HTAP)
Association for Retarded Citizens
1522 K Street, N.W., Suite 516
Washington, DC 20005

NAHB/National Research Center
400 Prince George's Boulevard
Upper Marlboro, MD 20772

This is a case study of the Reservoir Cooperative, Madison Mutual Housing Association in Madison, Wisconsin. In addition to describing the advantages and disadvantages of this model, the paper provides information on different structures for cooperatives and alternative financing sources for cooperatives, including mortgage insurance, national cooperative boards, the Federal National Mortgage Association (FNMA) secondary market for cooperative blanket and share loans, state and local government agencies, tax exempt bonds, home ownership assistance programs, equity financing, low income tax credits, foundation and religious organizations, local initiative support corporation (LISC) and enterprise foundations.

TITLE: Hands-on housing: A guide to mutual housing associations and community land trusts for residents and organizers

AUTHORS: Hovde, S., & Krinsky, J.

PUBLICATION INFORMATION: 1996

Community Services Society of New York
105 East 22nd Street
New York, NY 10010

"Many people suffer from a lack of decent, affordable, and accessible housing. In some areas, landlords have abandoned or neglected their rental housing...private, for-profit housing is increasingly more expensive than low-income households can afford, and does not meet their need for a safe and well-maintained home. In a number of neighborhoods, low-income residents and other community members have joined together in response to this unmet need."

Hands-on housing is a practical guide to help tenants and community activists survive the difficulties, and to explore the possibilities, of two new types of housing organizations, namely, Mutual Housing Associations and Community Land Trusts. Both housing organizations are non-profit and produce and maintain long term low- and moderate-income housing. Stories of the successes and failures of twenty such housing organizations are told and practical suggestions for maintaining "effective resident-community partnerships" are provided.

TITLE: The community land trust: A new system of land tenure

AUTHOR: Institute for Community Economics

PUBLICATION INFORMATION: 1986, June

Institute for Community Economics
151 Montague City Road
Greenfield, MA 01301

This paper presents an overview not only of what a land trust is but the principles that direct community land trusts. The problem of how we use our land today is defined followed by a CLT approach to dealing with these problems. The article takes the reader through a brief description of how the CLT works and describes advantages of such an approach.

TITLE: Your place or mine?: A handbook for home ownership

AUTHORS: Laux, B., & Moran-Laux, C.

PUBLICATION INFORMATION:

Creative Management Associates
P.O. Box 5488
Portsmouth, NH 03802-5488

The preparation of this handbook was supported by the Illinois Planning Council on Developmental Disabilities. It is intended as a guide to assist people who are seeking housing options in Illinois. However, the majority of the information provided would be useful to those in other states who are seeking housing. The manual begin with discussion about the importance of "home." The second chapter discusses the importance of relationships, as well as some practical strategies for meeting others and selecting compatible housemates, if that is an interest. Chapter 3 covers the issue of control of housing, such as responsibilities associated with rental versus home ownership, and describes various housing options including trusts, condominiums, and shared housing programs. Chapter 4 provides detailed information on home ownership, including: financing, zoning, interest, and taxes. Charts and text give specific financial information, such as about down payments and monthly mortgage and rental payments, and about determining what you can afford. Detailed information on budgeting for home ownership is given in Chapter 5. Sample budgets are included. Issues such as utilities, leases, repairs, and maintenance are discussed. Chapter 6 is most specific to Illinois, describing sources of housing assistance in the state; however, similar sources exist in other states. The appendix includes copies of forms for budgeting for a rental place, budgeting for a place you own, and a money payment schedule.

TITLE: A survey of legal and financial planning issues in the Home of Your Own (HOYO) Project

AUTHOR: Macintosh, J. D.

PUBLICATION INFORMATION: 1994

University of New Hampshire
Institute on Disability
7 Leavitt Lane, Suite 101
Durham, NH 03824

Based on the experience of supporting people in New Hampshire and other states to own homes, this article provides on overview of some of the "pitfalls and potential solutions" to legal and financial issues. It is divided into two major sections. The first section addresses how to preserve eligibility for and maximize the use of Medicaid benefits. The second section addresses Department of Labor and IRS issues such as how to arrange companion and roommate support.

TITLE: Extending the American dream: Home ownership through creative financing

AUTHOR: New Hampshire Home of Your Own Project

PUBLICATION INFORMATION: 1995

Institute on Disability
University of New Hampshire
7 Leavitt Lane, Suite 101
Durham, NH 03824

The Home of Your Own Project in New Hampshire was designed to promote home ownership for people with disabilities. One of the activities of this project was to demonstrate that people with developmental disabilities have the financial capacity to sustain home ownership and how services can be designed to support people in these situations on an ongoing basis. This report provides a profile of 16 people who now own their own homes through working with this project.

TITLE: Housing for people with severe disabilities: A collection of resource materials

AUTHORS: Prepared by O'Connor, S., & Racino, J. A. Updated by Hulgin, K., Walker, P., Fisher, E., Handley, M., & Shoultz, B.

PUBLICATION INFORMATION: 1995

Syracuse, NY: Center on Human Policy, Syracuse University.

This packet is an update of a 1990 information package and provides an introduction to housing strategies such as trusts, co-operatives, and subsidies. It offers information about organizations and other resources that should be helpful to individuals, their families, advocates, and service providers in the effort to develop home ownership opportunities.

TITLE: Housing policy and persons with mental retardation--A report of the working group on housing to the Presidential Forum: The President's reform agenda and people with mental retardation and the President's Committee on Mental Retardation

AUTHOR: President's Committee on Mental Retardation

PUBLICATION INFORMATION: 1995

President's Committee on Mental Retardation
Room 5325
300 Independence Avenue, S.W.
Washington, DC 20201
Contact: Gary Blumenthal

This report to the President's Committee on Mental Retardation lays out 10 broadly recommended goals in housing for persons with mental retardation, and then addresses 5 issues related to policy and programmatic actions that contribute to the Committee's efforts to achieve the goals. These 5 issues include:

- What is currently known about housing for persons with mental retardation and what needs to be learned about it?

- What are the emerging successful and promising practices in policy and programs in providing normal housing for persons with mental retardation?

- What is the nature and organization of current federal, state and local housing and associated programs that affect housing for persons with mental retardation?

- What are the existing challenges and barriers in current policy and practices that impede access to the housing people want and need?

- What should the federal and state governments do and encourage others to do that will improve access to appropriate desirable housing for persons with mental retardation?

TITLE: In search of housing: Creative approaches to financing integrated housing

AUTHORS: Randolph, F., Laux, R., & Carling, P.

PUBLICATION INFORMATION: 1987

Center for Community Change Through
Housing and Support
Institute for Program Development
Trinity College of Vermont
208 Colchester Avenue
Burlington, VT 05401

This monograph outlines and identifies effective resources in relation to housing opportunities for people with labels of mental illness. It highlights the economics of housing, offers more specific insight into understanding real estate language, and discusses private investor ownership and financing strategies for consumer and family ownership. An overview of government programs which finance housing on a federal, state and local level is included. Finally, this publication addresses issues of implementation of integrated housing offering a six step process of what should be looked at in such a pursuit. The reader is provided with a list of references and a bibliography. Though the text focuses on the mental health system, it offers a great deal of useful information applicable for people and agencies desiring to understand integrated housing for other individuals.

TITLE: Housing is for everyone: Affordable homes for people with disabilities

AUTHOR: Raymond, B.

PUBLICATION INFORMATION: 1992

The New Hampshire Developmental Disabilities Council
Concord Center
10 Ferry Street, Box 315
Concord, NH 03301

This booklet, though written to offer specific advice to New Hampshire residents, is a very good overview of housing options. It includes chapters that explain home ownership, public assistance programs, cooperatives, mortgage programs, and supports. The booklet is written clearly, simply, and includes concrete strategies.

TITLE: Coming home: Ex-patients view housing options and needs: Proceedings of a national housing forum

AUTHOR: Ridgway, P. (Ed.)

PUBLICATION INFORMATION: 1988

Center for Community Change
Through Housing and Support
Institute for Program Development
Trinity College of Vermont
208 Colchester Avenue
Burlington, VT 05401

This paper is based on a forum which called together a small group of ex-patients of the mental health system to discuss housing and support. The participants agreed that people with psychiatric disabilities want and need typical community housing (e.g., apartments, houses, cooperatives, etc.) with consumer-controlled support. Instead, they are usually forced into group living situations or single room occupancy hotels where they experience lack of privacy, lack of control over their home, transience, stressful interpersonal relations, even danger, and regimentation. The group discusses consumer preferences in housing, attitudinal barriers within the mental health profession, and the types of supports that should be available to enable people to live in the homes of their own choosing. This is an insightful piece that applies to any disability group.

TITLE: From a community residence to a home of their own

AUTHOR: Walker, P.

PUBLICATION INFORMATION: 1995

Syracuse, NY: Center on Human Policy, Syracuse University.

This report describes how the Syracuse Developmental Services Office in Syracuse, New York facilitated the process of home ownership for two women previously living in a community residence. The first part focuses on strategies for achieving home ownership, including collaboration with a local housing agency, financing, and how the mortgage company was approached. The second part of the paper discusses how in-home supports were arranged in order to assist the women to live in their home. The paper concludes with a summary of key factors that made this move possible.

TITLE: Community sponsorship of housing cooperatives

AUTHOR: Wilcox, R.

PUBLICATION INFORMATION: 1987

National Association of Housing Cooperatives
1614 King Street
Alexandria, VA 22314

This booklet discusses advantages and disadvantages of housing cooperatives, what community sponsors can expect from a cooperative, types of housing cooperatives in the United States, and information on how to start a cooperative. The booklet also discusses mutual housing associations (MHA) which are not used extensively in the United States, but may be in the future.

A MHA is housing produced, owned and operated by a not-for-profit, public interest organization where those who develop the housing and those who will live in it join together in membership. The MHA is the umbrella organization that then can sponsor single and multifamily non-profit cooperatives, condominiums and rental housing. The booklet is brief and offers a good overview of some basic questions related to housing cooperatives.

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4. Supporting People with Challenging Behaviors

From the massive literature on supporting people with challenging behavior, we have selected a very small number of resources. Our criterion for selection was adherence to the guidelines of TASH on intrusive interventions, which read as follows:

> Whereas, in order to realize the goals and objectives of TASH, including the right of each severely handicapped person to grow, develop, and enjoy life in integrated and normalized community environments, the following resolution is adopted:
>
> > Whereas, educational and other habilitative services must employ instructional and management strategies which are consistent with the right of each individual with severe handicaps to an effective treatment which does not compromise the equally important right to freedom from harm. This requires educational and habilitative procedures free from indiscriminate use of drugs, aversive stimuli, environmental deprivation, or exclusion from services; and
> >
> > Whereas, TASH supports a cessation of the use of any treatment option which exhibits some or all of the following characteristics: 1) obvious signs of physical pain experienced by the individual; 2) potential or actual physical side effects, including tissue damage, physical illness, severe stress, and/or death, that would properly require the involvement of medical personnel; 3) dehumanization of persons with severe handicaps because the procedures are normally unacceptable for nonhandicapped persons in community environments; 4) extreme ambivalence and discomfort by family, staff, and/or caregivers regarding the necessity of such extreme strategies or their own involvement in such interventions; and 5) obvious repulsion and/or stress felt by nonhandicapped peers and community members who cannot reconcile extreme procedures with acceptable standard practice;
> >
> > Resolved, that The Association for Persons with Severe Handicaps' resources and expertise be dedicated to the development, implementation, evaluation, dissemination, and advocacy of educational and management practices which are appropriate for use in integrated environments and which are consistent with the commitment to a high quality of life for individuals with severe handicaps.
>
> (Adopted October, 1981)

These guidelines mean that most of the standard materials on behavioral interventions were excluded from consideration. We feel that the highly vulnerable nature of people who are labeled as having "challenging behaviors" justifies such rigid adherence to these guidelines. We also include a few materials related to people with disabilities who have become involved with the criminal justice system.

TITLE: Sometimes you just want to feel like a human being: Case studies of empowering psychotherapy with people with disabilities

AUTHORS: Blotzer, M., & Ruth, R.

PUBLICATION INFORMATION: 1995

Baltimore: Paul H. Brookes Publishing Co.

Case studies of psychodynamic counseling with children and adults labeled developmentally disabled demonstrate behavioral changes and improved life satisfaction resulting from interventions. Although the psychotherapeutic perspective provides for some unusual interpretations of behaviors and their meanings (e.g., "...this was the only way [client] could cope with massive losses without decompensating into psychosis" [p. 16]) this perspective allows for the fact that some behaviors are relatively fixed. Thus accommodations, not remediation, are often acknowledged as the most fruitful approach to many problems. The book opens new avenues for thinking in an area of psychology that has been dominated by behaviorism for three decades.

TITLE: Severe learning disabilities and challenging behaviors

AUTHORS: Emerson, E., McGill, P., & Mansell, J.

PUBLICATION INFORMATION: 1994

Champman & Hall
206 Boundary Row
London SE1 8HN
UNITED KINGDOM

This book examines a comprehensive range of issues related to supporting individuals who challenge families and service providers with their behaviors. It is full of excellent ideas based on cases about everything from the roots of behavior to creating community options. Some of the chapters may be of limited use to American readers as the authors analyze issues based upon British policy and systems.

TITLE: An educative approach to behavior problems: A practical decision model for interventions with severely handicapped learners

AUTHORS: Evans, I. M., & Meyer, L. H.

PUBLICATION INFORMATION: 1985

Baltimore: Paul H. Brookes Publishing Co.

This book presents a decision model, accompanied by detailed procedures for implementation, for dealing with the excess or problem behavior of persons with severe disabilities in a functional and adaptive way. Practitioners are provided with a practical, step-by-step model for planning interventions with people who have severe problem behaviors in the context of habilitative, community-based programs across the school years and beyond. Separate chapters describe current "most promising practices" in educational curricula for learners with severe handicaps into which this approach should be integrated; the empirical research base on causes of and interventions with severe behavior problems; a field-tested decision model to select priority intervention goals within the context of the IEP; strategies to intervene with excess behavior in normalized, community environments; and evaluation principles and procedures to judge the significance of interventions. Each of the procedures and strategies described in the book have been demonstrated to be effective in integrated, community settings, and all are consistent with the TASH resolution on intrusive interventions.

TITLE: Use of aversive procedures with persons who are disabled: An historical review and critical analysis

AUTHORS: Guess, D., Helmstetter, E., Turnbull, H. R., & Knowlton, S. (Ed. by P. Campbell, with Epilogue by F. Laski)

PUBLICATION INFORMATION: 1987

TASH
29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204

This monograph presents a thorough and scholarly critique of the use of aversive procedures such as punishment, negative reinforcement, and overcorrection with people with disabilities and especially severe handicaps. The manual includes an evaluation of the effectiveness of aversive procedures, an analysis of aversive procedures as described in published studies, a comparison of procedures used on

people with disabilities with those used on other populations, a discussion of public and professional silence on aversives in the area of disabilities, a description of depersonalization, and a summary and recommendations. The manual contains an exhaustive list of references and a series of excellent tables summarizing the research literature on aversive procedures.

This monograph will be most useful to policymakers, researchers, and others who are involved in the controversy surrounding the use of aversive procedures with people with disabilities. Those who oppose aversives generally will find support for their position, although the authors concentrate on analyzing aversive interventions rather than demonstrating the feasibility of alternatives. A strength of this manual from one perspective is a weakness from another. The authors attempt to provide an objective and balanced analysis of the issues relating to the use of aversives. If anything, they understate the case against aversive procedures. While this approach may be effective in reaching people undecided in the controversy, the manual lacks a sense of moral outrage at the punishment and pain too often inflicted upon people with disabilities.

TITLE: Behaviour self!: Using behavioural concepts to understand and work with people with developmental disabilities

AUTHOR: Hingsburger, D.

PUBLICATION INFORMATION: 1996

Diverse City Press Inc. (La Presse Divers Cite Inc.)
BM 272, 33 des Floralies
Eastman, PQ J0E 1P0
CANADA

This is the first of a planned 3-book series in understanding people with developmental disabilities and helping them gain greater control over their world, their life, and their behaviour. At the beginning, the authors lays out some critical foundation points: (1) All behaviour communicates and as such behaviourists or those who wish to use behaviourism must see behaviour as a legitimate language that needs decoding; (2) Anyone who attempts to program away a behaviour without understanding its meaning is unethical. We don't need to be right, but we need to have tried to interpret the language. (3) Behaviour programming when successful should leave people in more control of their lives, not just their behaviour. (4) Behaviour programming when unsuccessful should blame the hypothesis not the client or staff. (5) People with disabilities are complex people, just like those without disabilities, and as such will require a broad palate of services from art therapy to play therapy to psychoanalysis. Behaviour therapy is not always the treatment of choice. (6) Medication is not an evil thing. Like behaviour therapy, it should not be used to

control people, but to assist them with control. Since some people without disabilities benefit from appropriate medication so will some people with disabilities; (7) A person who uses behaviour approaches will soon see that the behaviour often communicates about an inappropriate environment or inappropriate treatment. As such the therapist will become, very quickly and often very radically, an advocate. (8) There can be no one philosophy that determines how a diversity of people live. Using behaviour technology to eradicate personal difference and personal choice is an Aryan concept that is very scary. The following pages are filled with stories, examples, and strategies for assisting people to gain more control of their behaviour and their lives.

TITLE: A problem solving approach to challenging behaviors: Strategies for parents and educators of people with developmental disabilities and challenging behaviors

AUTHORS: Janney, R., Black, J., & Ferlo, M.

PUBLICATION INFORMATION: August 1989

SETRC
Syracuse City School District
501 Park Street
Syracuse, NY 13203

Why do some children with developmental disabilities behave in ways that are difficult to handle? Are some behavior problems so serious that they legitimate aversive treatment, pain infliction or the causing of emotional distress? If one chooses not to punish, how does one respond to behaviors that are disturbing and dangerous? These are questions that are constantly raised by both parents and educators of children who are developmentally delayed. There are a number of ethical questions and issues of humane treatment that are also closely associated with the above mentioned queries. This manual therefore offers various non-aversive alternatives to address severe behavior problems at home, at school and in the community.

The repertoire of problem solving strategies that are offered in this book can be characterized as gentle, preventative, normal, educational, individualized and ongoing. It involves effective planning through a team approach that avoids placing blame and emphasizes honesty and accountability. The authors offer valuable suggestions on how to define the particular behavior problem, ways of prioritizing aspects of the behavior that need to be changed, methods of gathering information, developing a sound theory and acting on it in non-aversive and humane ways. The manual contains blank problem solving forms that can be used for any behavior intervention.

This manual is a very useful resource for professionals and parents. Written in a simple style and explained thoroughly with adequate examples, it is easy to comprehend.

TITLE: Alternatives to punishment: Non-aversive strategies for solving behavior problems

AUTHORS LaVigna, G. W., & Donnellan, A. M.

PUBLICATION INFORMATION: 1986

Irvington Press
740 Broadway
New York, NY 10003

This book provides a comprehensive overview of how to implement a positive approach to behavioral programming in the community. It reviews the standard behavioral practices and delineates how they can be implemented within this positive framework. This book will be particularly valuable to behavioral psychologists working with community programs.

TITLE: Cognitive counseling and persons with special needs: Adaptive approaches to the social context

AUTHOR: Lovett, H.

PUBLICATION INFORMATION: 1985

Praeger Publishers
521 Fifth Avenue
New York, NY 10175

This book is about seeing the unique value of every individual regardless of the labels society has pasted on them. Indeed, Lovett does write about the counseling--the true professional--relationship in the fullest sense: helping the individual have the greatest possible range of choices in his or her life. The forum for this discussion is provided as Lovett highlights the ways in which behaviorism, a powerful tool for aiding personal growth, has been transformed into a methodology for control. In particular, he shows how an emphasis on clinical research has led to the misuses of many interventions in the lives of people with severe disabilities. His central point is that by attempting to directly translate procedures used in highly controlled institutional settings into the real lives of people, service providers and their behavioral consultants have frequently lost sight of the individual they claim they are helping. Lovett sees the basic principle of behaviorism as remaining valuable, but points out how implementation is radically transformed when the social context of an intervention is taken into consideration.

This book is written in a clear understandable style. Anyone with a minimal understanding of behaviorism should be able to learn from it. However, you will be disappointed if you pick this volume up looking for a how-to-do-it-manual of behavioral strategies. One of its central lessons is that all such "resources" will be most valuable when they find their way to the circular file.

Teachers, residential providers, and consultants will find Lovett rewarding reading. In addition this book may be particularly valuable as a tool for educating local "generic" mental health providers and beginning psychologists about people with severe and profound mental retardation. One of the most telling sections contains the author's reflections on the inadequacy of his own professional preparation for working for people with severe disabilities.

And finally, make no mistake about it, as Lovett speaks about the right to live in the community, freedom of choice, respect, and dignity he clearly means everyone. His numerous examples from his own experience make it clear that he places no arbitrary limits on who is a member of the human community. His book should lead all of us who work for people with severe disabilities to seriously examine the attitudes we bring to our work.

TITLE: Learning to listen: Positive approaches and people with difficult behavior

AUTHOR: Lovett, H.

PUBLICATION INFORMATION: 1996

Baltimore: Paul H. Brookes Publishing Co.

This book is filled with strategies and case studies that illustrate alternatives to ineffective and controlling practices so often used with people who have intellectual or emotional disabilities. It is through an interactive "learning to listen" that support providers can develop positive approaches that support people to take greater control of their lives. Chapters cover issues such as the politics of labeling, the politics of behaviorism, and the hierarchy of control. Final chapters of the book discuss some stories of people who hurt themselves and some concluding choices and challenges.

Lovett concludes, "It is in listening to people with difficult behavior that positive approaches contrast most clearly with current traditions of service. In our world of positive approaches, we work in collaboration and in a spirit of openness, honesty, and equality...In some ways, the sharpest contrast can be seen between nonaversive behavioral strategies and positive approaches. Nonaversive strategies are behavioral controls with a pleasant face...Positive approaches are about behavior changes through personal growth and mutual responsiveness...Nonaversive technologies are about control and behavior change; positive approaches are about cooperation and personal growth" (pp. 232-233).

TITLE: Gentle teaching: A non-aversive approach to helping persons with mental retardation

AUTHORS: McGee, J. J., Menolascino, F. J., Hobbs, D. C., & Menousek, P. E.

PUBLICATION INFORMATION: 1987

Human Sciences Press, Inc.
72 Fifth Avenue
New York, NY 10011

This book presents "gentle teaching" as a positive and humanizing approach to dealing with people who have challenging behaviors. As described by the authors, gentle teaching rejects punishment and aversive behavioral interventions and stresses the importance of integrating behaviorism with humanism. The book provides a philosophical rationale for gentle teaching, a description of techniques, examples of gentle teaching, and a response to common questions about gentle teaching ("What you can try if...?"). Throughout the book, the authors present concrete suggestions. The book is directed toward caregivers and others who are directly involved in providing services to people who have challenging behavior.

This book will be most useful to people who are committed to nonaversive interventions and do not need to be convinced that aversive procedures are ineffective and dehumanizing. The authors do not attempt to present the research evidence on the effectiveness of either aversive interventions and punishment, on the one hand, or gentle teaching, on the other. The strengths of this book are that it presents a humanizing posture toward people who have often been abused and dehumanized and that it offers some practical ideas.

TITLE: Against pain as a tool in professional work on people with severe disabilities

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1989

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

"Those with professional power over people with severe disabilities face an ethical question: is it good to use pain as a tool in their work?" O'Brien tells us that the answer to the questions is "No." His argument is that regardless of whether pain appears to work as a behavior control mechanisms and regardless of the call by both

proponents and advocates for more research on the effectiveness of pain as a tool, the fact remains that "pain as a tool increases the power professionals have over vulnerable people while it decreases the changes of positive human relationship." This monograph helps those who are against the use of pain as a tool in professional work on people with disabilities clarify their beliefs and formulate arguments against the use of this "tool."

TITLE: The language of pain: Perspectives on behavior management

AUTHORS: Rioux, M. H., & Yarmol-Franko, K. (Eds.)

PUBLICATION INFORMATION: 1988

The G. Allan Roeher Institute
4700 Keele Street, Kinsmen Building
York University
North York, ON M3J 1P3
CANADA

The language of pain is a collection of essays by professionals, family members and self-advocates who believe it is wrong and ineffective to use painful "therapies" in managing behavior. Especially powerful is the description by a woman of her sister's experiences in traditional behavior management programs. As her sister's behavior became more injurious, more painful techniques were used on her, while the family stood by helplessly, unable to bring her home and unable to stomach the assaults on her dignity and person. Each writer makes a strong plea for a more humane approach to altering or dealing with abusive behavior.

The book argues for understanding, human bonding, and interaction as the basis for attempts to change behavior. It points out that methods that have nothing to do with the infliction of pain can be used with success by professionals and families. The book presents a good and impassioned plea for change but is not a "how-to" manual. Instead, it is valuable because it emphasizes the beliefs and postures that must underlie any attempt to interact with another human being.

TITLE: Autism and life in the community: Successful interventions for behavioral challenges

AUTHOR: Smith, M. D.

PUBLICATION INFORMATION: 1990

Baltimore: Paul H. Brookes Publishing Co.

One area that is often neglected by policy makers, researchers and professionals is the area of adult issues in autism. This book seeks to fill this gap. It provides practical guidelines that meet the "training and management needs" of persons with autism, that can be used in the context of community integrated school and residential settings. The book thus effectively answers questions on the service systems that are provided, behavioral assessment, intervention and modifications that can be implemented and vocational skills that can be taught. An interesting section of the book deals with self management and interpersonal skills which prove to be particularly useful to the adult, especially in the context of community living. A number of examples have been used to effectively illustrate the techniques that have been described.

Though the strategies that have been offered are useful in analyzing and problem-solving of behavioral challenges, this book falls short on one score. By describing a highly structured and manipulable environment and with the increased utilization of "technical" terms to describe and explain behavior, there is a certain human element that is missing in the book. Behavioral challenges also arise through an inability to create and sustain meaningful relationships with others. And this is one aspect that the book does not even touch upon.

TITLE: Supporting people with severe reputations in the community

AUTHORS: Smull, M. W., & Harrison, S. B.

PUBLICATION INFORMATION: 1992

NASDDDS
113 Oronoco Street
Alexandria, VA 22314

This monograph may prove useful to anyone planning with, or supporting a person with "behavioral challenges." The handbook focuses on four key issues: labeling, individualized planning, recruitment and development of supports, and ways to identify and avoid problems or abuses.

Case studies are used extensively to demonstrate how individuals often considered "not ready" for community living can be supported safely and well. Opportunities for choice and control are emphasized. The authors stress the importance of teaching support personnel how to respond to the wishes and needs of the individual before target behaviors are expressed.

EDUCATION IN THE REGULAR CLASSROOM

This is an exciting time to review materials on education for students with severe disabilities. The books and articles in this section, for the most part, reflect an approach which emphasizes functional curricula, community-based instruction, and full integration in regular classrooms in neighborhood schools. Several present issues for children in specific age groups (such as preschool or school-age) or having specific disabilities (such as autism or chronic illnesses). Others apply to students across a range of age groups or disabilities, or have separate chapters that look at these issues. The publications included in this section address school integration strategies and approaches, although not all support full integration in regular classes.

TITLE: Creating tomorrow's schools today: Stories of inclusion, change, & renewal

AUTHORS: Berres, M. S., Ferguson, D. L., Knoblock, P., & Woods, C. (Eds.)

PUBLICATION INFORMATION: 1996

New York: Teachers College Press.

"Why restructure schools so that children of all abilities can be active and contributing members of their school communities? This book suggests that the complex process of creating homes within our schools for all children is a worthwhile endeavor, not only for children with disabilities, but for all members of the school community" (p. 1).

This book demonstrates that the groundwork for inclusion is most successful in general education, as a centerpiece of school restructuring The authors begin by examining several areas that indicate a reason for change, including the influence of political and social justice, innovative instruction and curriculum, the school as community, and personal experience. Then, the book presents a number of examples of inclusive school communities. Through these case studies, the authors emphasize and promote a genuine commitment and a process of change that would result in schools making equal academic efforts for all children.

TITLE: Achieving the complete school: Strategies for effective mainstreaming

AUTHOR: Biklen, D.

PUBLICATION INFORMATION: 1985

New York: Teachers College Press

This book clearly examines principles and strategies for use in achieving successful integration of students, including those with severe disabilities, into regular classrooms in neighborhood schools. Although there are separate chapters to address the particular role of several different groups--district special education administrator, school building principal, teacher, and parent--they emphasize and show that each group becomes "more effective when it understands the basic nature of the other groups' roles."

Co-authors of specific chapters include Robert Bogdan, Stanford J. Searl, Jr., Steven J. Taylor, and Dianne Ferguson. The areas examined include not only special education/regular education issues, such as principles for curriculum planning, but also the basic aspects of organization and change that make mainstreaming work. Numerous case examples illustrate the complexities involved in mainstreaming, the relationship of the process to the culture of schools, and the many critical issues affecting the integration of special and regular education. Based on the experiences of scores of administrators, teachers, and parents, the material in Achieving the complete school has been drawn from two extensive studies funded by the National Institute of Education and the U.S. Department of Education, and carried out simultaneously over three years.

TITLE: Schooling without labels: Parents, educators, and inclusive education

AUTHOR: Biklen, D.

PUBLICATION INFORMATION: 1992

Philadelphia: Temple University Press.

Starting with the question, "is there any place within the culture where integration already exists such that we could study it, learn from it, and apply principles from it to schools and other social settings?" Biklen closely examined the experiences of six families whose children with disabilities are full participants in family life. From his examination, Biklen is able to show that people with labels of disability are able to be full participants in many areas of life. However, contradictions exist between social policy and practices and life in the family for these people. This book teaches us how the principles of inclusion can be extended beyond family life to schools, community, and other social institutions.

TITLE: Special education does not mean special classes: Two parents' observations about Louisville, Kentucky's experiences in integrating special and regular education systems and students

AUTHORS: Brost, M., & Johnson, T.

PUBLICATION INFORMATION: 1986

Wisconsin Coalition for Advocacy
16 North Carroll Street, Suite 400
Madison, WI 53703

Two parents of children with several substantial disabilities have written this informative monograph that provides observational, non-evaluative descriptions of five programs in Louisville where children with significant disabilities are integrated into regular education classes. All the five programs are based on the valued educational goal that students with severe disabilities should be taught to function in a regular school environment, to interact appropriately with their non-handicapped age peers and to form friendships with some of those age peers. Yet, systemic or administrative and individual innovations have contributed to the development of five very different examples of restructuring existing funding sources and arranging physical space and staff time to support integration. The monograph gives detailed descriptions of each program, and points out the advantages, disadvantages and general issues raised by each approach.

TITLE: Speechless: Facilitating communication for people without voice

AUTHOR: Crossley, R.

PUBLICATION INFORMATION: 1997

New York: Penguin Books, Ltd.

In 1974, Rosemary Crossley was introduced to teenager Annie at an Australian institution for children with severe disabilities. Annie has cerebral palsy and was unable and was unable to communicate in a conventional sense of the word. However, together Rosemary and Annie figured out a means by which Annie could communicate. Annie learned to type using a communicator. Rosemary then went on to help a number of other people with disabilities and of various ages to communicate through the use of methods now housed under the name of facilitated communication. In this book we read about Annie, Derek, Michael, Carolyn, and Penny and their journey into this world of communication.

TITLE: Inclusive and heterogeneous schooling: Assessment, curriculum, and instruction

AUTHOR: Falvey, M. A. (Ed.)

PUBLICATION INFORMATION: 1995

Baltimore: Paul H. Brookes Publishing Co.

This text is another wide ranging collection of chapters by a variety of authors, all with the view of including all children in schools, with particular emphasis on students with more severe disabilities. The first few chapters introduce the issues, including a history of services for children with disabilities, as well as the history of general education. There is a chapter on collaboration, as well as another on assessment to develop curriculum. This last chapter is followed by several detailed appendices showing an example of how to develop curriculum for a student with a severe disability. Several chapters focus on integrating services into the classroom, including motor skills and communication skills. In addition, there is one on how to create a classroom that is supportive of a diverse student body, as well as how to help all students develop and maintain friendships. Of particular interest for some people may be a chapter on inclusive preschool education. It is unusual for a book on inclusive education to include preschool issues, and this is a valuable addition.

TITLE: Curriculum decision making for students with severe handicaps: Policy and practice

AUTHOR: Ferguson, D. L.

PUBLICATION INFORMATION: 1987

New York: Teachers College Press

All too often, curricular goals like functional/community-based instruction, competitive work, and participation in community domestic and recreational activities have been dismissed as being unfeasible options for students with severe disabilities. By taking as data the meaning of curriculum to teachers, this fascinating and thought-provoking book analyzes the implications of these curricular goals for students with severe disabilities and looks at how secondary school teachers have translated and implemented these goals in their own classrooms.

The author concludes that, while new public policy mandating education for severely handicapped students has generated substantial changes, both systemic and individual, the reform has not been extensive enough to overthrow prevalent standards

of productivity that measure human worth in terms of earning capacity. Thus, although many severely handicapped students increasingly participate in heterogeneous communities, too many do not and will not. It is the author's contention that teachers contribute to this failure by assuming its inevitability and denying their students the opportunity even to fail.

TITLE: Integration strategies for students with handicaps

AUTHOR: Gaylord-Ross, R. (Ed.)

PUBLICATION INFORMATION: 1989

Baltimore: Paul H. Brookes Publishing Co.

Written as an introductory textbook for regular and special educators in training, this book represents a commitment to progressive inclusion for students with handicaps. The book is divided into three main sections: (1) the education of students with different types of disabilities; (2) innovative techniques in integration; and (3) the ecology of delivering services to persons with disabilities. Each chapter provides practical information, with actual teaching techniques in real situations being put forth.

While the strategies for specific disabilities are helpful, it is important for the reader to recognize the fact that each student is an individual first, and that there are no prescribed techniques for specific disabilities. It would be erroneous for the reader to conclude that this is a "cookbook" for integration and disability. The innovative techniques for integration span a wide spectrum of options, and provide the reader with some interesting ideas.

TITLE: Choosing options and accommodations for children: A guide to planning inclusive education

AUTHORS: Giangreco, M. F., Cloninger, C. J., & Salce Iverson, V.

PUBLICATION INFORMATION: 1993

Baltimore: Paul H. Brookes Publishing Co.

This is a manual that is designed to be used by teachers and others to develop a plan to include all children in classrooms. The authors state in their introduction that although many books describe the benefits of inclusion, and may have sections on certain aspects, there are few how-to books available. This book starts to fill that void. They start out with a number of assumptions that form the basis of their planning guide, which are values that include the importance of the child's family in an

educational plan, as well as the need to utilize collaborative teamwork. The first part of the manual shows how to set learning priorities within the context of the child's family. The second section shows how to translate these priorities into classroom goals, both long and short term. This includes the identification of any accommodations needed, and supports for the child in the classroom. The third part of the manual gives step by step instructions on how to implement the plans in an inclusive classroom. This last section is followed by a thorough list of references, as well as appendices that contain examples and sample forms referred to during the three main sections of the manual.

TITLE: Integrating general and special education

AUTHORS: Goodlad, J. I., & Lovitt, T. C. (Eds.).

PUBLICATION INFORMATION: 1993

Macmillan Publishing Company
866 Third Avenue
New York, NY 10022

The contributors to this book write on various issues in addressing how to educate all children in an equitable way in our schools. It should be noted that while some of the chapters describe ways to combine regular and special education in an inclusive setting, others do not. The first two chapters of the book describe the background of the issues, and look at the separate and unequal tracks of education, depending on an educational label. In the third chapter, one of the editors describes the issues that need to be addressed when integrating education; these issues are further discussed by other authors in the rest of the book. While the chapter on curriculum design assumes the inclusion of all children in a regular classroom, the authors of a chapter on comprehensive delivery systems go to great lengths to describe what "all" children means, and do not necessarily gear their chapter to inclusive education. However, one chapter written by a school principal is a valuable addition to the book, as are chapters on how to restructure schools and help teachers to adapt to combining general and special education.

TITLE: Cultural diversity, families and the special education system

AUTHOR: Harry, B.

PUBLICATION INFORMATION: 1992

New York: Teachers College Press.

This book offers a parent perspective on the special education process and offers a broad understanding of some of the cultural issues and disadvantages that come into play when families become involved in the special education system. The book is based on in-depth study of 12 Puerto-Rican American families and their experiences and perspectives related to the educational system.

TITLE: Improving educational outcomes for children with disabilities: Principles for assessment, program planning, and evaluation

AUTHOR: Kozloff, M. A.

PUBLICATION INFORMATION: 1994

Baltimore: Paul H. Brookes Publishing Co.

"Education can be of great benefit to children with disabilities and their families. It can bring children into the social world, help them acquire needed skills, and enable them to enjoy the richness of experience that is taken for granted by persons without disabilities." However, Kozloff reminds us that more often than not "the promise of education" for children with disabilities is unfulfilled. Furthermore, program evaluation is rarely carried out in manner that reveals how instruction may be altered to better facilitate progress for children. In this book the author discusses, through the use of numerous stories from his personal experience, issues regarding program assessment that include: educational aims, effects of social distance, common human needs, models of standard behavioral repertoires, socially insensitive assessments, learning through interactions with environments, families of children with developmental disabilities, coordinated and empowering programs, interviewing, and direct observations.

TITLE: Issues in the education of students with complex health care needs

AUTHORS: Lehr, D. H., & Noonan, M. J.

PUBLICATION INFORMATION: 1989

In F. Brown & D.H. Lehr (Eds.), Persons with profound disabilities: Issues and practices (pp. 139-160). Baltimore: Paul H. Brookes Publishing Co.

This chapter begins by stating that with improved technology and the principle of normalization, children with complex health care needs are increasingly participating in public school settings. The authors state that they are looking

specifically at students who have severe handicaps, including mental retardation. Medically, many students need medical technology in every facet of their lives. Special health care needs include infectious diseases such as hepatitis B and AIDS, feeding tubes, catheterization and respiratory difficulties. One of the issues for these students and their families in whether or not the school district is responsible for paying for medical and nursing care while the student is in school. An issue that directly follows this is who in the school is responsible for administering the medical care. The authors conclude that more research needs to be done in this area, as little is known even about how many children have complex health care needs.

TITLE: Extraordinary children, ordinary lives: Stories behind special education case law

AUTHOR: Martin, R.

PUBLICATION INFORMATION: 1991

Champaign, IL: Research Press.

This book is a collection of case studies "selected to illustrate the basic principles one needs to understand special education law." Chapter 1 gives an overview of the problems parents faced that caused Congress to pass PL 94-142. Chapters 2 through 6 treat the need for evaluation, consider what is meant by appropriate education, discuss how the IEP plan must specially design the educational offering, examine the role of related services, and illustrate the requirement for services to be provided in the least restrictive environment. Chapters 7 and 8 describe how students qualify for extended school year and extended school day programs. Finally, Chapters 9 through 12 cover the responsibility of the state education agency, the importance of the impartial hearing officer, and the potential for parents to be reimbursed for educational costs and attorneys' fees.

TITLE: Strategies for teaching exceptional children in inclusive settings

AUTHORS: Meyen, E. L., Vergason, G. A., & Whelan, R. J. (Eds.)

PUBLICATION INFORMATION: 1996

Love Publishing Co.
Denver, CO 80222

This comprehensive text is a useful resource for teachers and others who are looking for a guide to include all children in an inclusive environment. There are four basic sections to this book, and each one outlines specific ways to include all students. The first section is on curriculum and instruction, and there are several chapters on how to collaborate to serve children's diverse needs. These chapters describe specific ways to make collaboration work, while several other chapters look at issues such as educational standards for all students, as well as a chapter on effective co-teaching. The second section of this book is based on assessing the needs of all students in an inclusive classroom. The chapters in this section describe alternatives to traditional classification systems that most schools currently utilize. While one chapter specifically addresses children with learning disabilities, the other chapters on assessment are applied to all students.

The third section of this book focuses on classroom management for teachers in inclusive classrooms. This section does not take the traditional approach that children's behavior is managed as a euphemism for punishment, but instead shows how discipline for all students can be built into each classroom. Of particular interest is a chapter on dispute resolution within classrooms, where students resolve their own conflicts. The fourth and final section of the book is on collaboration, which brings together issues from the other chapters right into the classroom with all school personnel involved. One chapter focuses particularly on how special and general educators can best work together, augmented by specific examples. Another chapter explores the issue of consultation within the inclusive classroom, and how it can add to collaborative efforts.

TITLE: Information for parents of high school students with disabilities in transition to adult life

AUTHOR: Minnesota Department of Education

PUBLICATION INFORMATION: 1993

Real World Publications
9357 Cortland Court
Woodbury, MN 55125

This booklet was designed to help students, parents, and educators prepare for the transition from high school to adult life. Discussions and checklists are provided on the following issues: parents tips for planning, student's viewpoints, making decisions, supported employment, transition roles, role of the student in preparing for transition, the role of the parents and the professionals, student participation in staffing, the importance of keeping records.

TITLE: Cooperative learning and strategies for inclusion

AUTHOR: Putnam, J. (Ed.)

PUBLICATION INFORMATION: 1993

Baltimore: Paul H. Brookes Publishing Co.

This book is designed to assist educators in meeting the needs of a diversity of learners--children with varying cognitive abilities; developmental and learning difficulties; sensory impairments; and different cultural, linguistic, and socioeconomic backgrounds--in inclusive classrooms. The objective of the book is to provide teachers, teaching assistants, administrators, support personnel, families, community members, and other professionals with suggestions for effectively implementing the cooperative learning approach in heterogeneous classrooms and schools. Chapters discuss the theoretical and empirical background of cooperative learning, as well as practical suggestions, case studies, illustrative examples, and lesson plans.

TITLE: Collaborative teams for students with severe disabilities: Integrating therapy and educational services

AUTHORS: Rainforth, B., York, J., & Macdonald, C.

PUBLICATION INFORMATION: 1992

Baltimore: Paul H. Brookes Publishing Co.

This book serves as a guide to help professionals who work with children with severe handicaps to employ team work in educational settings. The authors state that as people with severe disabilities are integrated into the community, so educators should integrate their roles to help children in schools. The authors are all trained as therapists, such as physical therapists and speech and language therapists; their main point is to integrate these kinds of services into the daily routines of students. The first section of the book provides a framework for a collaborative model. This includes a philosophical rationale, as well as legal. An important chapter in this section discusses the topic of including parents as a part of the student's team. The second section gets into planning stages of collaboration, and gives many examples. The focus is on the students within the educational settings, with professional intervention as secondary. The chapters take the reader through collaborative assessment, designing an educational plan, and curriculum adaptations. Finally, the third section describes implementation of collaborative education, giving many specific ideas on how to keep the team working well together.

TITLE: Curriculum considerations in inclusive classrooms: Facilitating learning for all students

AUTHORS: Stainback, S., & Stainback, W. (Eds.)

PUBLICATION INFORMATION: 1992

Baltimore: Paul H. Brookes Publishing Co.

The focus of this book is on ways to adapt educational curriculum for all students in regular classrooms, including those with the most severe disabilities. The first section of the book introduces the concept of inclusive education, and gives some information on implementing inclusion in a classroom. Another part of the first section advises school personnel on figuring out what kinds of curriculum are appropriate for every student in an inclusive classroom. The second section of this book is the largest, and contains seven chapters on actually adapting curriculum, and utilizing it in the classroom. Most of these chapters address specific issues. For example, one chapter by the editors and another author describe using curriculum adaptation to create inclusive classrooms, while another describes how to integrate support personnel into inclusive classrooms. The book's third section brings up other issues related to educational curriculum, such as a chapter on how to include all students in extracurricular activities. In addition, there is a chapter written by parents of children with disabilities; they give feedback on how to include all parents. The book closes with a chapter on the challenges of curriculum in inclusive classrooms.

TITLE: Inclusion: A guide for educators

AUTHORS: Stainback, S., & Stainback, W. (Eds.)

PUBLICATION INFORMATION: 1996

Baltimore: Paul H. Brookes Publishing Co.

This text is divided into six basic sections. The first is an introduction to inclusion, with one chapter devoted to the rationale for inclusion, another that gives an historical overview of inclusion in this country, and a third that discusses inclusion as a force for school renewal. The second section of the book is entitled Basic strategies, and there are a number of different issues presented. Among the more useful chapters in this section is a description of MAPS, Circles of Friends, and PATH. These are presented as tools that teachers may utilize, as a creative way for a community to support someone with a disability. The third section of the book is on collaboration, and many of these chapters focus on building friendships and building community.

The fourth section looks at curriculum issues, with some chapters that provide concrete ways to plan curriculum, along with real life examples. Children's behavior in the inclusive classroom is the topic of the fifth chapter. These chapters are designed to assist teachers in setting up a successful classroom right from the beginning to prevent behavior problems, as well as give some information on dealing with problems as they arise. The last section of the book includes a chapter on the positive influences that inclusion has on the self-identity of people with disabilities; another focuses on the importance of having the support of the community and family for inclusive schools; and a third providing some concluding remarks regarding concerns about inclusion.

TITLE: Educating all students in the mainstream of regular education

AUTHORS: Stainback, S., Stainback, W., & Forest, M.

PUBLICATION INFORMATION: 1989

Baltimore: Paul H. Brookes Publishing Co.

This book is an excellent compilation which addresses the merging of special and regular education. Six major areas are outlined in the text: (1) an introduction and historical overview of education integration and a rationale for merging special and regular education; (2) three case examples of situations involving integration; (3) strategies for enhancing quality and equality in heterogeneous integrated schools; (4) educational practices for integrated classroom settings; (5) broadening integration and equality beyond schools through family participation and community participation; and (6) concerns relevant to the education of students in integrated schools and classrooms. This book would appeal to a wide range of readers including all teachers, parents, students, administrators and advocates.

The organization of this book is excellent. Throughout the text there are "points to ponder" which challenge the reader. The chapter on assessment procedures for the classroom relies heavily on quantitative approaches, and could have included qualitative strategies as well.

TITLE: Support networks for inclusive schooling

AUTHORS: Stainback, W., & Stainback, S.

PUBLICATION INFORMATION: 1990

Baltimore: Paul H. Brookes Publishing Co.

There has been much discussion in the field of education regarding full inclusion of students who have disabilities in the regular classroom. For those who have embraced this philosophy, this volume will provide assistance with the actual nuts-and-bolts of promoting friendships among all students. The book is divided into three sections: part one describes inclusive schooling and support networking; part two focuses on specific supports that can be utilized to assist students and classroom teachers; part three emphasizes how parents, administrators, and community members can work together to create supportive and caring schools.

This book will be very helpful for teachers who want to know more about the nature of providing support to students who have disabilities in their classroom, as well as how they, as teachers, can acquire their own support. Parents will find this book helpful also in determining what the potential is for their child's well-being in the school setting, with the proper supports in place. The editors have done an excellent job of combining many thoughtful chapters from a variety of concerned individuals in the field of education.

TITLE: Creating an inclusive school

AUTHORS: Villa, R. A., & Thousand, J. S. (Eds.)

PUBLICATION INFORMATION: 1995

Association for Supervision and Curriculum Development
1250 N. Pitt Street
Alexandria, VA 22314

Villa and Thousand have edited a number of books on inclusive education, and this one is a real asset for teachers, parents and members of the community. The first chapter starts out with describing the basics of inclusion, presenting several perspectives on what inclusive education means. This is followed by a short chapter written by a "regular parent" of a child in school, who documents his conversation with his son who notices a peer with a disability being removed from his classroom. An historical perspective of inclusive education is also given, as well as a description of the philosophy and rationale for creating inclusive schools.

The place where this book shines is its chapters written by parents and teachers of children with disabilities. These chapters bring to life the philosophy described by the professionals, and make the book accessible for a variety of readers. In addition, one chapter by a person with a disability is a powerful asset to the book. There are also several chapters on adapting curriculum to the needs of all students, and how to plan for change to an inclusive school. A straightforward chapter on questions that teachers, administrators and parents may have on creating an inclusive school is also included, and the authors give advice on how to promote an inclusive school, as well as resources to tap into.

TITLE: Restructuring for caring and effective education: An administrative guide for creating heterogeneous schools

AUTHORS: Villa, R. A., Thousand, J. S., Stainback, W., & Stainback, S. (Eds.)

PUBLICATION INFORMATION: 1992

Baltimore: Paul H. Brookes Publishing Co.

The editors of this book have included many chapters by various authors on merging special and regular education together, for the use of school administrators. The book is premised on the notion that the public educational system needs to serve all children with excellence and equity. It is divided into four major sections, containing several chapters each. As an interesting organizing point, one author introduces each section with an article that gives a wedding as an analogy to combining all education. For example, the introduction to the section entitled Supports for heterogeneous schooling is described as, advice for getting along with the in-laws and other people who know you well. As these titles indicate, the book acknowledges the difficulties of merging all education together, and has a lot of sage advice on moving toward this goal. While some of the authors of the numerous chapters are university professors, others are administrators, and even an elementary school principal. Many examples are given of schools that became communities where all children are valued, and where every child's needs are met in a regular classroom. This text will be a useful guide for districts to plan for heterogeneous schools, and for parents and advocates to demonstrate to administrators that there are examples to follow.

TITLE: Transition from school to work: New challenges for youth with severe disabilities

AUTHORS: Wehman, P., Moon, M. S., Everson, J., Wood, W., & Barcus, J. M.

PUBLICATION INFORMATION: 1988

Baltimore: Paul H. Brookes Publishing, Inc.

Preparing to make the transition from high school into the adult working world presents new challenges for high school students with disabilities; challenges that often were, and are, seen as daunting. Transition from school to work provides useful suggestions grounded in real life examples that will help students, their families and

their teachers, prepare for this transition. Specifically, the book focuses on a transition of three steps: 1) prepare for the transition in the school years, 2) initiate transition program planning, and 3) develop employment options and placements for students. A number of checklists are provided to help all involved smooth the transition process.

INTEGRATED EMPLOYMENT: SERVICES AND SUPPORTS

Some of the most exciting and creative progress is community integration of people with severe disabilities is now being make in efforts to place and support people in regular jobs in the community where they earn a decent wage and have opportunities to interact with nondisabled people. As is always the case in fast moving fields, the literature lags behind the exciting progress being made in this area. With this in mind the following reviews provide basic information to those who are interested in supported work. There is a vast amount of literature in this area. The material here does not represent a comprehensive coverage. Instead, we have selected a sampling of literature in the field.

TITLE: Supported employment: A community implementation guide

AUTHORS: Bellamy, G. T., Rhodes, L., Mank, D., & Albin, J. M.

PUBLICATION INFORMATION: 1988

Baltimore: Paul H. Brookes Publishing Co.

This book begins with an introduction to key supported employment issues and an overview of program models and organizational accomplishments. According to the authors, the five key organizational accomplishments are: (1) paid employment opportunities are available; (2) work performance meets employer requirements; (3) employees are integrated; (4) ongoing support needs are met; and (5) organizational capacity is maintained. The chapters that follow describe strategies for implementing a supported employment program, from planning, to staff training, business participation, the role of families and friends, and the role of state leadership.

TITLE: Consumer advocacy and supported employment: A vision for the future

AUTHORS: Brooke, V., Barcus, M., & Inge, K. (Eds.)

PUBLICATION INFORMATION: 1992

Rehabilitation Research and Training Center on Supported Employment
Virginia Commonwealth University
P.O. Box 842011
Richmond, VA 23284-2011

This manual was written by the editors and some co-authors, including a number of self-advocates who took part in a consumer focus group. The first part of the book, written by the editors, introduces some issues related to consumer advocacy and supported employment. They discuss both the parallels between consumer advocacy and supported employment, as well as some of the challenges. The second part, written by members of the focus group, discusses issues and concerns raised during the focus group. These include: (1) career development; (2) choice; (3) systems barriers; (4) families; (5) consumer and professional partnerships; (6) qualifications not education; (7) affordable and accessible housing; (8) access to assistive technology; (9) consumer feedback to professionals; (10) supported employment group options; and (11) referral and/or resource system. The third part of the manual, entitled "A Consumer Empowerment Approach to the Design of Human Service Systems: Implications for Supported Employment," is written by John Kregel. This includes discussion of the concept of consumer empowerment, implications for supported employment, and recommendations for systems change. The fourth and final section of this book, by Ed Turner, presents strategies for effective consumer advocacy. This is a good resource for consumers and for service agencies that are striving to provide more individualized, person-centered supports.

TITLE: Supported employment handbook: A customer-driven approach for persons with significant disabilities

AUTHORS: Brooke, V., Inge, K. J., Armstrong, A. J., & Wehman, P. (Eds.)

PUBLICATION INFORMATION: 1997

Rehabilitation Research and Training Center on Supported Employment
Virginia Commonwealth University
P.O. Box 842011
Richmond, VA 23284-2011

This first chapter in the book lays out a description of a customer-driven approach to supported employment, including discussion of values, best practices, role of the employment specialist, and other issues in implementing the customer-driven approach. Subsequent chapters focus on organizational marketing, developing a customer profile, job development, employment selection, job site training, and long-term supports. The final chapter discusses quality in relation to supported employment services, including quality indicators, assessing quality, and successful partnerships.

TITLE: The Madison strategy for evaluating the vocational milieu of a worker with severe intellectual disabilities

AUTHORS: Brown, L., Udvari Solner, A., Schwartz, P., Courchave, B., Kampschroer, E. F., VanDeventer, P., & Jorgensen, J.

PUBLICATION INFORMATION: 1991

TASH
29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204

This volume's purpose is to delineate a strategy that can be used to evaluate the vocational milieu of a worker with severe intellectual disabilities. It offers an alternative to many of the currently used vocational evaluation strategies and is based on the assumption that all people with severe disabilities can work in integrated environments. This volume has been underway since 1986, and has gone through four revisions. It was sent out for review to selected agencies, service providers, and public schools that are involved in vocational training, and was extensively revised based on their input. The latest version has been field-tested with 45 local individuals, and contains a checklist covering the evaluation areas.

TITLE: Keys to the workplace: Skills and supports for people with disabilities

AUTHORS: Callahan, M. J., & Garner, J. B.

PUBLICATION INFORMATION: 1997

Baltimore: Paul H. Brookes Publishing Co.

The introductory section of the book discusses the issues of: values and employment, individualized planning, the dynamic nature of support, the role of family, and the importance of social relationships. The second section describes a seven-phase sequence for fostering natural supports: (1) communicate natural ways (of job performance, etc.); (2) promote natural means (of job training, etc.); (3) utilize natural people (supervisors, co-workers, etc.); (4) facilitate successful performance; (5) support/assist/substitute for natural people; (6) reconsider natural means; and (7) adapt/modify/change natural ways. Detailed descriptions and strategies are provided for each step. The final section of the book presents some specific strategies for systematic instruction in the workplace.

TITLE: A working relationship: The job development specialist's guide to successful partnerships with business

AUTHORS: Fabian, E. S., Luecking, R. G., & Tilson, Jr., G. P.

PUBLICATION INFORMATION: 1994

Baltimore: Paul H. Brookes Publishing Co.

The basic premise of this extremely worthwhile book about supported employment is that job development specialists need to form working partnerships with employers, to replace the "beg, place, and pray" approach that has characterized job placement agencies in the past with "...a new ethic of quality service and customer satisfaction" (p. 4). The authors rely on business concepts to "reinvent" the role of supported employment staff in relation to business. The new role which they promote is a very practical one. Speaking from their own experience with using this approach, the authors attest to its great potential for success. This is a good handbook for agencies that are attempting to move to a more partnership-oriented model.

TITLE: Toward supported employment: A process guide for planned change

AUTHORS: Gardner, J. F., Chapman, M. S., Donaldson, G., & Jacobson, S. G.

PUBLICATION INFORMATION: 1988

Baltimore: Paul H. Brookes Publishing Co.

Conversion from sheltered to integrated employment is a major change for an organization. This valuable book's premise is that such change can be managed successfully. The book begins by concisely summarizing existing theory and knowledge about change, including methods for introducing change, design of strategic and long range action plans, and coping with internal and external resistance to change. It emphasizes involvement of all affected parties in the change process, including board members, staff at all levels, people with disabilities, parents, and community organizations. This book goes on to apply the conceptual material to conversion more specifically to supported employment, discussing such areas as leadership, organization readiness, market analysis, assessing staff needs, skills, and capabilities, organizational structure needed to maintain supported employment, and coordination with other human service providers and private sector organizations. The authors insist that the values and norms of the organization are critical to the change process, and properly emphasize the need to clarify and communicate these throughout the process.

It is up to the reader, however, to define the values used to drive the change process, as the authors only suggest some general values. This may but does not need to present problems for readers who prefer the individualized placement approach.

TITLE: Vocational education for persons with handicaps

AUTHOR: Gaylord-Ross, R. (Ed.)

PUBLICATION INFORMATION: 1988

Mayfield Publishing Company
1240 Villa Street
Mountain View, CA 94041

This comprehensive textbook describes the multifaceted process of career preparation for students with disabilities. It is divided into four major sections having to do with vocational special education. The first part, dealing with policies and professional roles, contains chapters on legislation and policy, career education, professional roles and practices, and community living. The second section, on vocational assessment and preparation, looks at assessment, programming, and secondary vocational training. The third section describes and explores economic issues, the business perspective, the ecology of the workplace, and adult employment programs. The last section contains four chapters that look at vocational education for persons with different lives or types of disabilities--mild disabilities, severe disabilities, physical disabilities, and sensory disabilities. While the authors of these chapters include well-known writers in every aspect of the field, readers may have difficulty with their complexity. Several chapters are excellent, however.

Ian Pumpian, Elizabeth West, and Holly Shepard, for example, contributed a chapter entitled "Vocational Education and Persons with Severe Handicaps." This chapter starts by raising some fundamental value questions that provide the basis for developing and evaluating services for people with severe disabilities. The authors argue that consistent answers to such questions are essential to understanding the current direction and debate concerning training and employment. The authors also criticize some of the current supported employment practices, for example, for either excluding people with the most severe disabilities or selecting pseudointegration models, as has been the case with some enclave and work crew programs. The chapter reviews some of the school trends and initiatives that have contributed to the evolution of supported work and discusses current trends and initiatives in adult services.

TITLE: Vocational education for students with handicaps

AUTHOR: Gaylord-Ross, R.

PUBLICATION INFORMATION: 1989

In D. Biklen, D. L. Ferguson, & A. Ford (Eds.), Schooling and disability: Eighty-eighth yearbook of the National Society for the Study of Education, Part II (pp. 203-231). Chicago: University of Chicago Press.

In this chapter the author describes a qualitative study of vocational integration of people with developmental disabilities in five European countries: Denmark, Great Britain, Italy, Switzerland, and West Germany. Based on five months of travel through these countries, where the author conducted numerous site visits; completed over 250 interviews; and reviewed 500 documents, the author describes patters of vocational integration in these five countries, as compared to efforts underway in the United States. The author concludes by identifying and discussing five important variables which can facilitate social change toward integrated work: (1) "political will," (2) the presence of a "charismatic leader(s)," (3) the presence of a "model demonstration program," (4) the level of "instructional technology" among staff, and (5) the "economic state" of a particular country.

TITLE: The social integration of supported employees: A qualitative study

AUTHOR: Hagner, D.

PUBLICATION INFORMATION: 1989

Syracuse, NY: Center on Human Policy, Syracuse University.

This study examines the social interactions that occurred within supported employment settings in Syracuse, NY, between workers with disabilities and their co-workers without disabilities. It also examines the job supports at these work settings, to understand the relationship between formal support services and natural job supports.

This study should affect the supported employment field profoundly. Its major finding was that even though employees were physically integrated on their jobs, they were often socially isolated, not because of their disabilities but because of how their jobs were set up. That is, their jobs tended to be structured in ways that inhibited natural social customs. The author, who spent hundreds of hours observing co-worker interactions on jobs, found that workers talk, joke, and give assistance to each other on a regular basis, and that there is often an informal mentoring system by which new

workers are socialized into jobs. He concluded that job coaches sometimes bring a human service perspective and a narrow job task focus to a work setting, being unaware of or ignoring the wider "culture" of a workplace. Many supported employment services will recognize themselves in his descriptions of practices that tended to exclude supported employees from participating in the workplace culture, which could have been a powerful source of natural support.

TITLE: Getting employed, staying employed: Job development and training for persons with severe handicaps

AUTHORS: McLoughlin, C. S., Garner, J. B., & Callahan, M. (Eds.)

PUBLICATION INFORMATION: 1987

Baltimore: Paul H. Brookes Publishing Co.

This excellent and practical book investigates the processes involved in developing jobs in integrated settings, and methods for facilitating employment opportunities for people with severe disabilities. The first part deals with the problems of sheltered work. Based on an analysis of cost effectiveness and programmatic ideologies, the first chapter demonstrates how these workshops are inherently inadequate. The authors suggest that sheltered work environments should be systematically phased out in favor of employment in integrated settings. The rest of the book serves as a practical manual for job development, placement and training for people with severe disabilities. This book provides unusually valuable guidelines for people who are interested in developing integrated individualized jobs for people with severe disabilities.

TITLE: Helping persons with severe mental retardation get and keep employment: Supported employment issues and strategies

AUTHORS: Moon, S. W., Inge, K. J., Wehman, P., Brooke, V., & Barcus, M. J.

PUBLICATION INFORMATION: 1990

Baltimore: Paul H. Brookes Publishing Co.

This book was written to address the exclusion of persons with severe and multiple disabilities from supported employment training and placement programs--an exclusion that is well documented at this point in time, despite the fact that this is the

group for whom supported employment was intended. This book provides information specifically related to helping people with the most severe disabilities get and keep real jobs in regular work places.

The first half of the book examines a variety of issues, including strategies for assessment, present performance outcomes for people with severe mental retardation, and job placement for students in transition to adulthood, and should challenge the reader to recognize what remains to be done in implementing supported employment. The last five chapters are more technical in nature, and can serve as a day-to-day guide for persons directly involved in programs. These chapters describe methods that have worked and that can be replicated. This is an excellent resource for program administrators and staff as well as parents and people in state decision-making positions.

TITLE: Closing the shop: Conversion from sheltered to integrated work

AUTHORS: Murphy, S. T., & Rogan, P. M.

PUBLICATION INFORMATION: 1995

Baltimore: Paul H. Brookes Publishing Co.

This excellent book about conversion of sheltered workshops to integrated employment begins by talking about the history of workshops and goes on to present a detailed case study on conversion. The authors describe the conversion of Pioneer, a small workshop for people with visual impairment (and, often, other labels as well), into supported, community employment. Comprehensive interviews with workshop participants spanning six years are utilized to gain insight into their perspectives on working in the shop, leaving it, and working in the community. The authors conclude that "...nearly every workshop participant demonstrated that he or she could achieve significant employment and community living success," which "...in fact stood in marked contrast to participants' files, which contained reports that were overwhelmingly negative, highlighted shortcomings, portended community failure, and often neglected participants' perspectives" (p. 110). Other examples of successful workshop conversions are given in an informative chapter entitled, "Leadership for Change," and the book concludes with some practical lessons that can be applied by those seeking to convert workshops and the policy reasons why such conversion is critical.

TITLE: Achieving success in integrated workplaces: Critical elements in assisting persons with severe disabilities

AUTHORS: Nisbet, J., & Callahan, M.

PUBLICATION INFORMATION: 1987

In S. J. Taylor, D. Biklen, & J. Knoll (Eds.), Community integration for people with severe disabilities (pp. 184-201). New York: Teachers College Press.

This chapter provides an overview of the elements of successful job placements for people with severe disabilities. Specifically the authors outline the rationale for a fully individualized approach to job placement, including methods for coordinating services across the various agencies which are usually involved in the life of a person with a severe disability. The authors also address key issues related to supports and skill development with special emphasis given to natural supports and the development of on-the-job relationships.

TITLE: The process of supported employment and quality of life

AUTHORS: Pedlar, A., Lord, J., & Van Loon, M.

PUBLICATION INFORMATION: 1989

Centre for Research & Education in Human Services
P.O. Box 3036, Station C
Kitchener, ON N2G 4R5
CANADA

This report contains the results of a qualitative research study examining the issues of supported employment and quality of life. It is based on in-depth interviews with 12 individuals with developmental disabilities who were involved in supported employment, as well as additional interviews with others who knew these people well. Chapter 1 provides an introduction to the study; Chapter 2 focuses on supported employment experiences; Chapter 3 presents quality of life issues; and Chapter 4 summarizes the research findings and discusses implications for the future of supported employment. Two of the key factors in positive supported employment experiences were: (1) the employer communicated in a direct and straightforward manner with the employee; and (2) the employment support worker facilitated the process of work integration by ensuring that it was the employee who took ownership

of the position and that others in the workplace related directly with the employee. Other critical issues raised by study participants included: concerns about getting beyond entry-level jobs; and ongoing financial uncertainties.

TITLE: Employment for all! A guide to employment
and
Employment for all! A guide for employers

AUTHOR: People First of Canada

PUBLICATION INFORMATION: 1996

Toronto: People First of Canada.

In March of 1996, People First of Canada hosted a national employment forum called Employment for all! Included in the many results of this forum were the above two guidebooks. The first guidebook is a guide for people with disabilities on how to find a job. Written with the help of People First members and using their own stories as examples, this monograph discusses employment issues such as, finding a job, keeping a job, why would you want to get a job, why some people do not want to have a job, having a job, working, applications, and resumes. The second guidebook provides members' advice for employers on hiring a person with a disability. Topics discussed are: why should you hire someone with a label, how to give someone a job and how to help him or her keep that job, having an employee with a label, and giving people a chance.

TITLE: Supported employment: Models, methods, and issues

AUTHOR: Rusch, F. R. (Ed.)

PUBLICATION INFORMATION: 1990

Sycamore Publishing Company
P.O. Box 133
Sycamore, IL 60178

This is a comprehensive book (25 chapters) covering many aspects of supported employment, with an emphasis on support as the hallmark of the approach and integration as its most defining contribution. This first 14 chapters, which deal with historical developments, experiences in several states, characteristics of programs, and methods, include some good discussions of worker-directed placement and promoting natural support and social acceptance. The chapter on worker-directed placement, for

example, emphasizes the importance of organizing services so that workers with severe disabilities are assisted to achieve employment and other life goals, that are personally defined, rather than controlled or established by the service provider. In this discussion, the worker provides the guidance and the professional the technology the worker uses to realize his or her choices. The difficult process of transformation of traditional supported employment services to a program that understands and supports consumer choices is explained and a model for doing so is proposed.

The next 7 chapters focus on issues in supported employment, including incentives and disincentives, cost-benefit analysis, conversion from adult day care, current national issues, and future opportunities, questions, and concerns. A final section focuses on the transition from school to work, looking at secondary vocational training, community planning, personnel preparation, and state planning.

TITLE: Future frontiers in employment of minority persons with disabilities

AUTHORS: Walker, S., Belgrave, F. Z., Nicholls, R. W., & Turner, K. A. (Eds.)

PUBLICATION INFORMATION: 1991

Howard University
Research and Training Center for Access to
Rehabilitation and Economic Opportunity
2900 Van Ness Street, N.W.
Holy Cross Hall, Suite 100
Washington, DC 20008

This monograph presents proceedings from a national conference on the future of employment for minority persons with disabilities that was held in 1990. It looks at four areas: policy implications, new frontiers in multicultural approaches, the future in assistive technology, and advancing frontiers through collaboration. Each section offers a number of articles illustrating the issues in relation to a variety of minority groups as well as raising national policy issues.

TITLE: Building bridges to independence: Proceedings of the national conference

AUTHORS: Walker, S., Fowler, J. W., Nicholls, R. W., & Turner, K. A. (Eds.)

PUBLICATION INFORMATION: 1988

Howard University
Research and Training Center for Access to
Rehabilitation and Economic Opportunity
2900 Van Ness Street, N.W.
Holy Cross Hall, Suite 100
Washington, DC 20008

This report documents "...the first nationwide meeting focusing on issues concerning the employment of Black Americans with disabilities" (p. v). These written accounts of some of the major presentations which were made at the conference are of great interest with regard to understanding the particular issues involved in assisting African Americans with disabilities to obtain and keep good jobs.

TITLE: Employment opportunities and career development

AUTHOR: Wehman, P.

PUBLICATION INFORMATION: 1993

In P. Wehman (Ed.), The ADA mandate for social change (pp. 45-68). Baltimore: Paul H. Brookes Publishing Co.

This chapter focuses on the implications of the ADA for employment opportunities and career development for people with a range of disabilities. It discusses the services that presently exist and how they can be improved as new opportunities are developed. The chapter is based on three themes: (1) the impetus for equal work opportunity promulgated by the ADA; (2) appropriate values of normalization (i.e., real work for real pay with a focus on careers for people with disabilities); and (3) existing research, which provides for an underlying empirical base for the type of adult/vocational service. A rationale for work and full employment for people with disabilities is the overriding theme of this chapter. In addressing full employment, numerous types of work options, including consumer driven alliances with local business and industry, are described. Also, the combined efforts of different local and state agencies, which can greatly influence vocational outcomes in respective states for persons with disabilities, are discussed.

TITLE: Supported employment and opportunities for integration

AUTHOR: Wehman, P.

PUBLICATION INFORMATION: 1993

In P. Wehman (Ed.), The ADA mandate for social change (pp. 69-88). Baltimore: Paul H. Brookes Publishing Co.

While the ADA does not specifically address the concept of supported employment in the law or its regulations, the author feels that the underlying theme of the ADA, competitive work in a nondiscriminatory work environment, is highly consistent with supported employment. "The ADA does not focus on specific support mechanisms but instead requires a broader framework for business and societal change to develop reasonable accommodations." The chapter begins with a brief overview of the concept of support employment. Following sections discuss the ADA and supported employment, models of supported employment, and individual examples of successful supported employment. The final parts of the chapter focus on consumer advocacy and supported employment.

RECREATION AND LEISURE OPPORTUNITIES

This section highlights some excellent materials on supporting children and adults in integrated community recreation and leisure activities. These materials emphasize the importance of such activities and decry the lack of attention by the field to people's needs to enjoy ordinary community leisure settings and events.

TITLE: Inclusive leisure services: Responding to the rights of people with disabilities

AUTHOR: Dattilo, J.

PUBLICATION INFORMATION: 1994

Venture Publishing, Inc.
1999 Cato Avenue
State College, PA 16801

The intent of this book is to encourage providers of leisure services to promote inclusion of people with disabilities into their programs. In bringing the spirit of the Americans with Disabilities Act to the field of recreation and leisure, this book attempts to provide current and future professionals with strategies that will facilitate meaningful leisure participation by all participants, while respecting the rights of people with disabilities. To achieve this end, this book contains three sections. The first section is devoted to awareness of important concepts. The second section presents readers with the American with Disabilities Act and specific strategies to facilitate compliance with the spirit of the Act. The final section presents some examples about specific individuals with disabilities in order to illustrate various strategies for including them in community leisure services.

TITLE: Leisure connections: Enabling people with a disability to lead richer lives in the community

AUTHORS: Gold, D., & Crawford, C.

PUBLICATION INFORMATION: 1988

The G. Allan Roeher Institute
York University, Kinsmen Building
4700 Keele Street
North York, ON M3J 1P3
CANADA

This manual provides many useful ideas and strategies for promoting integrated leisure and friendship opportunities for people with disabilities. Emphasis is placed on the importance of leisure in people's lives, based on a broad definition of leisure as including activities with others or alone, and activities that are more formal and organized as well as those that are informal and/or spontaneous. The authors also focus on the importance of friendships in people's lives, and the idea that it is people's relationships with others that give the most meaning to their leisure experiences.

The manual is designed for use by support groups or circles convened to assist a person with disabilities to develop and/or increase his or her leisure opportunities and connections. It outlines a 10-step process, which can be used to assist either children or adults. The recommended role of friends and other supports is one of a "facilitator" of increased connections and activities.

The 10 steps include thought-provoking questions and exercises to help guide group strategizing and planning. They focus on issues such as: thinking about the nature of leisure and the role it plays in everyone's lives; assisting the person to express wishes or dreams; developing a collective vision with the person; brainstorming about leisure options for the person, beyond just "programs" or classes; preparing for challenges that may be encountered; and on-going support and planning to increase and maintain leisure connections. The appendices contain additional information and ideas about the nature of friendship, as well as a sample listing of the many possible types of leisure opportunities can be found in a single community.

TITLE: The pursuit of leisure: Enriching lives with people who have a disability

AUTHORS: Gold, D., & McGill, J. (Eds.)

PUBLICATION INFORMATION: 1988

The G. Allan Roeher Institute
4700 Keele Street, Kinsmen Building
York University
North York, ON M3J 1P3
CANADA

This book is a collection of short chapters on integrated recreation and leisure for people with disabilities. It includes articles which provide strategies for service providers to promote integrated recreation opportunities, and articles about recreation

and leisure by both persons labeled as disabled and their parents. The chapters explore a range of issues, including: the development of "leisure identities" (reprint of an article by Judith McGill); integration through community associations and organizations; "regenerating community" (reprint of a paper by John McKnight); promoting cooperative versus competitive play; and leisure and friendships.

TITLE: Everybody belongs: Tips for including your child in community recreation

AUTHOR: Hackett, L. K.

PUBLICATION INFORMATION: 1994

New Hampshire Developmental Disabilities Council
10 Ferry Street, Unit 315
Concord, NH 03301-5004

Written by a parent of a child with a developmental disability, this book begins with discussion about the importance of recreation for everyone. It then discusses the law (ADA and IDEA) in relation to recreation. Subsequent chapters give suggestions and strategies for identifying your child's interests, identifying appropriate recreation programs, after-school recreation and summer recreation ideas, developing new activities when something it not available, and strategies to help develop and support friendships. While the resources listed in the appendix are specific to New Hampshire, the strategies and suggestions presented throughout will be useful for anyone wishing to promote increased opportunities for recreation.

TITLE: Integrating children and youth with disabilities into community recreation agencies: One agency's experience and recommendations

AUTHORS: Heyne, L. A., Amado, R. S., & Denelle, D.

PUBLICATION INFORMATION: 1987

The Jewish Community Center of the Greater St. Paul Area
1375 St. Paul Avenue
St. Paul, MN 55116

Since 1984, the Jewish Community Center of the Greater St. Paul area has conducted a model demonstration project to integrate children and youth with disabilities into the Center's regular programs and classes. The goals of the integration efforts have been three-fold: (a) to develop socialization and friendships between

youngsters with and without disabilities; (b) to teach new recreation and leisure skills; and (c) to provide opportunities for children and youth with disabilities to participate in normalized, everyday community activities.

This monograph contains information about integration at the Center in the following areas: rationale for integration; background to the project; funding; practical, step-by-step description of the integration process; networking with other community organizations; suggestions for managing challenging behaviors; Board of Directors and lay committee input and involvement; problems encountered and solutions generated; project outcomes; and forms for intake and evaluation. In conclusion, the authors emphasize the benefits of integration for all children, not only those with disabilities.

There is a wealth of information presented here about strategies for providing supports to children and youth with disabilities in a way that facilitates and enhances integration. It should be very useful for other agencies or individuals who are interested in promoting integration in recreation and leisure activities.

TITLE: Making friends: Using recreation activities to promote friendship between children with and without disabilities

AUTHORS: Heyne, L. A., Schleien, S. J., & McAvoy, L. H.

PUBLICATION INFORMATION:

Minneapolis: School of Kinesiology and Leisure Studies, Institute on Community Integration, University of Minnesota.

This handbook is the result of a 3-year program, the Dowling Friendship Program, which sought to understand and encourage friendships between children with and without disabilities, and a statewide survey of 484 community recreation agencies across Minnesota to identify inclusive recreation strategies. Chapters cover issues such as, "What Friendships Mean for Children," "What Inhibits Friendships?," "How to Encourage Friendships," and "How to Facilitate Friendship Development in Recreation Activities."

TITLE: IMPACT: Feature issue on inclusive recreation and families

AUTHORS: Heyne, L. A., Schleien, S. J., & Rynders, J. E.

PUBLICATION INFORMATION: 1996

Minneapolis: Institute on Community Integration, University of Minnesota.

This issue of IMPACT focuses on inclusive recreation for persons with developmental disabilities and their families. The articles included provide information about the benefits of inclusive recreation for individuals and families, the challenges in attempting to create or access community recreation services that offer inclusive programs, and strategies that can be used by parents in seeking out and advocating for quality inclusive programs for theirs sons and daughters who have developmental disabilities.

TITLE: Trying to play together: Competing paradigms in approaches to integration through recreation and leisure

AUTHOR: Human Services Research Institute

PUBLICATION INFORMATION: 1992

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, MA 02140

This monograph presents the results of a study of the recreational experiences of 12 people with disabilities. The first part provides an overview and methodology for the study; the second part presents individual case studies; and the third part contains concluding discussion and analysis. This study sought to discover what factors promote successful community integration within recreational and leisure settings. What emerged from the case studies was the interaction of and often contest between two distinct approaches--the recreational paradigm and the community membership paradigm. To the extent that the recreational approach was dominant, a platform for social integration was sometimes put in place. The realization of personal membership and relationships, however, seldom occurred. In those case studies in which the community membership approach was widely shared and understood, an impressive level of community integration was achieved within recreational settings and organizations.

TITLE: Leisure, integration and community

AUTHORS: Hutchinson, P., & McGill, J.

PUBLICATION INFORMATION: 1992

Leisurability Publications, Inc.
Box 281, Station A
Ottawa, ON K1N 6N5 CANADA

This is a comprehensive text book on leisure integration. It begins with an introduction that ties together issues of community and leisure. Subsequent chapters cover topics such as: devaluation and life experiences, person-centered approach to supporting people, new social roles, friendship, perspectives on community, empowerment, community building and community organizing, planning for change, coordination of services and supports, and educating for change. The book is a good resource for colleges and universities, as well as for people involved in facilitating integrated community leisure opportunities.

TITLE: Making school and community recreation fun for everyone

AUTHOR: Moon, M. S. (Ed.)

PUBLICATION INFORMATION: 1994

Baltimore: Paul H. Brookes Publishing Co.

This book begins with an overview of the case for inclusive school and community recreation. This is followed by Section One--Getting Started. The three chapters in this section describe strategies for successful inclusion in recreation programs, including community leisure facilitation and ways to find and create fun within a community. Section Two--Legal and Technical Supports discusses the impact of federal legislation on recreation programs, including environmental, material, and procedural adaptations to promote accessibility. The three chapters in Section Three--Ages and Settings: Inclusion Across the Life Span cover information on commercially available toys, inclusion of children in physical education, and strategies to promote inclusive recreation and leisure opportunities for adults. The fourth section, Inclusion in Action, describes additional examples of inclusive programs and strategies to promote inclusion. Throughout this book, the text is accompanied by an abundance of tables and figures offering detailed information and serving as useful tools for those for involved in creating inclusive recreation opportunities.

TITLE: SCOLA leisure activity fun guide

AUTHOR: Ray, M. T.

PUBLICATION INFORMATION: 1991

St. Paul: SCOLA of Ramsey County and the Minnesota Developmental Disabilities Council.

Minnesota Developmental Disabilities Council
300 Centennial Office Building
658 Cedar Street
St. Paul, MN 55155

This booklet describes the SCOLA (School and Community = Opportunities for Leisure Action) project, a joint effort between schools, students, parents, leisure services providers, and other interested community members. The focus of this project is on teens who are in their transition years (14-21 years of age). It includes information about identifying leisure interests, steps toward inclusion, forming an Advisory Committee, involving a Community Leisure Planner, planning with parents and care providers, and training leisure services staff.

TITLE: Together successfully: Creating recreational and educational programs that integrate people with and without disabilities

AUTHORS: Rynders, S. E., & Schleien, S. J.

PUBLICATION INFORMATION: 1991

The Arc of the United States
500 East Border Street, Suite 300
Arlington, TX 76010

The first chapter of this monograph presents the mandate for integration and discusses the importance of integrated options. Chapter 2 provides guidelines for promoting positive interactions. The next chapter offers many types of adaptations, with case studies to illustrate, while sample activity plans are presented in Chapter 4. The monograph concludes with a discussion of traits of quality integrated programs and profiles of several specific programs.

TITLE: IMPACT: Feature issue on integrated outdoor education/adventure

AUTHORS: Schleien, S. J., McAvoy, L., Lais, G., & Rynders, J. (Eds.)

PUBLICATION INFORMATION: 1991-92

Minneapolis: Institute on Community Integration, University of Minnesota.

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This newsbulletin describes successful approaches to outdoor education and high adventure in which persons with and without disabilities share the rewards of experiencing nature and of meeting challenges with a group of supportive peers. The benefits of integrated outdoor programs are discussed, and steps are identified toward developing and maintaining quality integrated options. A number of program examples are provided.

TITLE: Integrated outdoor education and adventure programs

AUTHORS: Schleien, S. J., McAvoy, L., Lais, G., & Rynders, J.

PUBLICATION INFORMATION: 1993

Sagamore
302 West Hill Street, P.O. Box 647
Champaign, IL 61824-0647

This book focuses on preparing individuals and environments for successful experiences in the outdoors. This text is about long-term, systemic change that is necessary so that people of all abilities and ages, including those individuals who significantly challenge the service delivery system, will be participating members of outdoor education and adventure settings. This practical, "how-to" guide takes an informative look at the integration process and presents a comprehensive framework for the provision of quality programs and activities. It offers a compelling rationale for the integration of outdoor education and high adventure. It also describes explicit administrative and programmative guidelines for simplifying the creation and implementation of successful inclusive services for people with and without disabilities.

TITLE: Community recreation and people with disabilities

AUTHORS: Schleien, S. J., Ray, M. T., & Green, F. P.

PUBLICATION INFORMATION: 1997

Baltimore: Paul H. Brookes Publishing Co.

This book begins with an overview of the historical background and philosophical basis of integrated recreation. Various chapters in the book provide detailed strategies for creating opportunities for inclusive recreation. One chapter focuses specifically on issues of bridges between families and community leisure service providers; another chapter focuses on promoting friendships in the context of

recreation/leisure activities. Chapter 8 provides information and discussion on evaluating community recreation programs, and Chapter 9 the authors offer descriptions of a number of exemplary programs. Extensive appendices provide a leisure interest survey, building access survey, directory of national organizations, evaluation forms, and an annotated bibliography.

TITLE: IMPACT: Feature issue on integrated leisure and recreation

AUTHORS: Schleien, S., & Rynders, J.

PUBLICATION INFORMATION: 1989

Minneapolis: Institute on Community Integration, University of Minnesota.

This newsbulletin contains brief articles describing indicators of quality integrated recreation programs; questions to assist in evaluating and selecting integrated recreation programs; strategies for parents as advocates; and features of several integrated recreation programs.

TITLE: Powerful partnerships: Parents and professionals building inclusive recreation programs together

AUTHORS: Schleien, S. J., Rynders, J. E., Heyne, L. A., & Tabourne, C. E. S.

PUBLICATION INFORMATION: 1995

Minneapolis: School of Kinesiology and Leisure Studies, Institute on Community Integration, University of Minnesota.

This monograph documents the efforts of parents and advocates working together to create inclusive recreation opportunities. Part one reviews the history of recreation in America and discusses the importance of inclusive recreation and the family's role in this. Chapters in Part Two describe family advocacy, family interaction with and collaboration with the serve system, and issues related to building friendships through recreation. Part Three provides descriptions of several inclusive programs, including a school-based friendship program, Parks and Recreation, a family-centered recreation program, and an intergenerational program at a neighborhood center. Finally, Part Four offers a vision for future inclusion in community leisure services.

TITLE: Community Leisure Integration Program: Program manual

AUTHORS: Thom, C., & O'Connor, M.

PUBLICATION INFORMATION: 1987

Madison, WI: Madison School-Community Recreation.

This manual describes the Community Leisure Integration Program, a project to promote the integration of youth with disabilities into community recreation programs/activities. The goals of the project include: increasing skills; having fun; promoting friendships; increasing independence; and promoting community environments that are inclusive. The manual contains information on staffing and administration of the program, as well as resource support materials in areas such as integration, social skills, friendship building, sexuality, assertiveness, teaching techniques, and advocacy strategies.

TITLE: Beyond the classroom: Involving students with disabilities in extracurricular activities at Levy Middle School

AUTHOR: Walker, P., Edinger, B., Willis, C., & Kenney, M. E.

PUBLICATION INFORMATION: 1988

Syracuse, NY: Center on Human Policy, Syracuse University.

This report describes efforts to involve students with severe disabilities from one classroom in extracurricular activities within their middle school. Students participated in activities such as intramural basketball, girls' volleyball team, track, the Spanish Club, the Computer Club, and the Ski Club. The paper provides detailed description of all aspects of the project, including: how it was conceptualized and structured; the role of the classroom teacher; the role of the support staff; and the perspectives of activity leaders (i.e., coaches, club advisors, etc.), parents, and other students on inclusion of students with disabilities in these extracurricular activities. This project provides a nice illustration of the cooperative effort between a human service agency and a public school in use of respite funds to provide supports for student participation in after-school activities. Examples are given which illustrate ways in which the students with disabilities experienced sense of school membership and school spirit that went far beyond the walls of the special education classroom.

BEYOND PAID SERVICES AND SUPPORTS

The resources in this division deal with a variety of issues that all of us, whether or not we have disabilities, see as basic needs in our lives. They are divided into the following sections:

1. Self-Advocacy
2. Advocacy
3. Families
4. Acceptance, Relationships and Community
5. Women and Caregiving

Self-advocacy and broader advocacy efforts are critical for people with disabilities and their allies. Additionally, there is much discussion today about informal support (i.e., support that is given based on arrangements or relationships that don't involve pay or a formal contract). The materials in the "Families," "Acceptance, Relationships and Community," and "Women and Care Giving" sections approach informal support from many perspectives.

1. Self-Advocacy

The fundamental right of speaking for oneself has long been denied to people with disabilities, who have usually had decisions made for them about every detail of their lives. They were, in other words, taught dependence. In the past twenty years, however, people with disabilities have organized movements (e.g., the self-advocacy movement, the independent living movement, the "psychiatric survivors" movement) that encourage and support people with disabilities to speak for themselves and determine their own futures. An exciting recent development has been that the leaders and members of the different movements are talking to and including each other, recognizing the commonalties between them and the issues they face.

The materials in this section emphasize the self-advocacy movement, which was organized by and for people with developmental disabilities, but the section includes materials produced by other groups as well.

TITLE: Read my lips -- It's my choice

AUTHOR: Allen, W. T.

PUBLICATION INFORMATION:

Governor's Planning Council on Developmental Disabilities
300 Centennial Building
638 Cedar Street
St. Paul, MN 55101

This easy-to-read resource guide is designed to help persons with disabilities increase their freedom of choice. Some of these areas of choice included in the guide are: consumer-based needs assessment (IPPs), planning for services, evaluation of services, understanding service systems, and self-advocacy. Each section includes how to carry out one of the areas. For example, the section on consumer-based service plans includes a discussion of: how a person can think about what he or she needs, important terms to know and understand when carrying out an individual person plan (IPP), making a list of your strengths, needs, and what you would like to work on in your life, getting ready for an IPP meeting, how to tell if your IPP is working, and so on.

TITLE: The power of self-advocacy: Making thunder

AUTHOR: Bowen, J.

PUBLICATION INFORMATION: 1994

In V. J. Bradley, J. W. Ashbaugh, & B. C. Blaney (Eds.), Creating individual supports for people with developmental disabilities (pp. 335-345). Baltimore: Paul H. Brookes Publishing Co.

Based on discussions at the 1990 People First of Connecticut statewide conference, self-advocates help us to look at some of the important issues that face self-advocates with regard to their rights to make decisions in their own lives over family/guardians' decisions. They also remind us that self-advocates together can "make thunder." This thunder can help them to take on institutionalization, the right to independent living, and to employment.

TITLE: Community Advocacy Press: People with Developmental Disabilities Speak Out for What They Believe

AUTHOR: Capabilities Unlimited

PUBLICATION INFORMATION

Capabilities Unlimited
2495 Erie Avenue
Cincinnati, OH 45208

Community Advocacy Press is a free, quarterly newsletter in which "people with disabilities write in their own words." All the articles in the newsletter are written by people with developmental disabilities in order to encourage self-advocates from across the United States to share what is happening in their life. Story topics in the first issue (Winter 1996) included the use of self-advocacy skills at post-secondary school, being listened to, legislative fact sheet, relationships, Operation Close the Doors, resources, and a conventions list.

TITLE: Learning about self-advocacy series

AUTHORS: Crawley, B., Mills, J., Wertheimer, A., Whittaker, A., Williams, P., & Billis, J.

PUBLICATION INFORMATION: 1988

Campaign for Valued Futures with
People Who Have Learning Difficulties
12A Maddox Street
London, W1R 9PL ENGLAND

What is particularly important about self-advocacy is that it enables the empowerment of individuals who have been always spoken for. This five volume guide does just this very effectively. Each of the five volumes begins with a "How to Use This Book" chapter. In this chapter, the authors encourage the individuals to use the book merely as support to the formation of their self-advocacy group. In this effort, the authors suggest that the books be used based on the group's specific needs and to find answers to their specific problems.

Each of these books deals with an interesting array of topics. The first book discusses the meaning of self-advocacy and its uses and helps to create an awareness of an individual's rights and responsibilities in a free society. The other books deal with some of the issues of setting up an advocacy group and the organizational guidelines that are necessary for its efficient functioning. There are also suggestions on networking with other groups and on dealing with issues of publicity. One of the most important features of the last book is that is highlights particular skills in areas that facilitate group dynamics like communication, listening, and being assertive.

A particularly strong feature of this set of books is the simple language that is used to communicate its intent. Another strength is that it emphasizes that it is alright to ask people for help if one needs it. In this effort it also offers a section on how to choose an advisor for the group who will not lead but empower. Each section in each

book has a number of exercises, and summaries of the important points that the section articulated. Also provided are a list of resources that could be used to complement the texts. In terms of a book that offers good suggestions, without being didactic, this book scores high.

TITLE: The last civil rights movement: Disabled People's International

AUTHOR: Driedger, D.

PUBLICATION INFORMATION: 1989

St. Martin's Press, Inc.
175 Fifth Avenue
New York, NY 10010

The disability movement appears to be the last of the social movements of the 20th century. At least this is the claim made by Driedger in this book. Based on interviews, reports, letters and documents by those involved in Disabled People's International, Driedger argues that people with disabilities have a distinctive history that cannot be in accordance with viewing them as clients, patients or deviants dealt with by professionals.

Driedger articulates what the Disabled People's International (DPI) defines as a disability: the inability of the social environment in the community to accommodate to the needs of people who have limitations. She also points out that historically people with disabilities had little to say in any of the policies that are affecting their lives. In light of these philosophies, DPI was born as an organization "of" handicapped individuals rather than an organization "for" handicapped individuals. The book goes on to describe the history of DPI, the early years of struggle to form an organization, and its goals and objectives.

One of the particularly redeeming features of this book is that it frankly voices the difficulties faced by an organization that claims to represent people with disabilities internationally. It lists the power politics among the "old boys" in the group, the elitism that often develops in leadership and the omission of people who are not powerful and who may have a voice in decision making. Of particular importance was the issue of people with disabilities in developing countries whose extreme poverty and lack of resources often prevented them from participating in DPI sponsored events. Also mentioned are difficulties, political and otherwise, that affect an organization of international dimensions.

This book has inherent value in that it attempts a realistic portrayal of a self-advocacy organization, including the challenges and struggles. It also very effectively places the field of disability in the context of a social movement that can effect social change in the field of today.

TITLE: New voices: Self-advocacy by people with disabilities

AUTHORS: Dybwad, G., & Bersani, H., Jr. (Eds.)

PUBLICATION INFORMATION: 1996

Cambridge, MA: Brookline Books.

"Self-advocacy by people with developmental disabilities was unthinkable three decades ago." This thinking changed when in the 1970s people with developmental disabilities started coming together to advocate for themselves. They began to organize themselves into groups to speak out and to organize themselves to fight against their experiences of social inequality. This book holds a collection of original papers, by self-advocates themselves, illustrating their movement. Papers come from self-advocates in Canada, England, the United States, Denmark, New Zealand, and Australia.

TITLE: How to be an effective board member: Manual for self-advocates
and
How to be an effective board member: Manual for facilitators

AUTHORS: Eddy, B. A., Cohen, G. J., & Rinck, C.

PUBLICATION INFORMATION: 1989, December

University of Missouri-Kansas City
Institute for Human Development
2220 Holmes, Room 321
Kansas City, MO 64108

These two manuals are valuable additions to the sparse literature on how self-advocates can be effective as board members. The materials in these two manuals can be used to train self-advocates, or can be used directly by self-advocates themselves. The manual for self-advocates contains many drawings and pictures illustrating the text, which describes meetings, rules, board members' rights and duties (e.g. the right to ask for clarification, the right to voice an opinion, the duty to maintain order and sometimes confidentiality, etc.), and presents samples of board orientation materials. While the examples used are based on Kansas City or Missouri services and boards, the manuals would be useful to people in other states.

TITLE: We are People First: Our handicaps are secondary

AUTHOR: Edwards, J. P.

PUBLICATION INFORMATION: 1982

Ednick, Inc.
Box 3612
Portland, OR 97208

When talking about disability, it would be important to blur the line between the "we's" and the "they's." This book is an effort in this direction. What happens when a group of former institutional residents who are tired of being misrepresented and devalued decide to do something about this? They form a self-advocacy group: People First. We are People First describes the origin of the movement and its philosophy.

"People First" was started on January 8, 1974. Since then it has grown into a movement that has effectively articulated the needs of its members who are self-advocates. The organization thus affords a chance to members to practice self-advocacy and self-assertion skills. A section of the book describes the early years, the difficulties, the conventions that were organized and the slow but steady growth of the organization into one of international dimensions. Some of the themes deemed important were the appreciation of help, the need and value for friends, pride in one's accomplishments and the negative effects of labeling. A section also describes how the members consider the role of the helper, an issue that today's self-advocates and professionals continue to struggle with.

This book makes fascinating reading. It describes how individuals who were formerly dismissed as nobodies and interred in institutions have managed to fight back and articulate a strong message. Behind the obscuring handicap is a person with dynamism and a vision to effect change.

TITLE: The self-advocacy workbook

AUTHOR: Gardner, N. E. S.

PUBLICATION INFORMATION: 1980

Technical Assistance for Self-Advocacy Project
Kansas Center for Mental Retardation and
Human Development UAP
University of Kansas
Lawrence, KS 66045

This is a resource for people with disabilities. It provides a framework for learning about self-advocacy, organizing a group, and undertaking group action to deal with issues of common concern. The materials are specifically geared for use by a group. Each chapter attempts to focus on only one discrete aspect of organizing. Also, the structure of each presentation is the same throughout in order to minimize any problems the group might have with the management of their meetings.

TITLE: IMPACT: Feature issue on self-advocacy

AUTHORS: Hayden, M. F., & Shoultz, B. (Eds.)

PUBLICATION INFORMATION: 1990/91

Minneapolis: Institute on Community Integration, University of Minnesota.

This bulletin contains numerous articles by self-advocates and supporters, who describe and discuss self-advocacy. Articles give information on a history of self-advocacy, starting local self-advocacy groups, self-advocates and the legislature, issues of choice, and information for self-advocates on boards and committees. The bulletin includes annotations of a number of self-advocacy resources.

TITLE: IMPACT: Feature issue on self-advocacy

AUTHORS: Hayden, M. F., & Ward, N. (Eds.)

PUBLICATION INFORMATION: 1994

Minneapolis: Institute on Community Integration, University of Minnesota.

This issue of IMPACT focuses on the growing self-advocacy movement and the issues it is raising. Articles written by self-advocates and supporters describe the history of the national self-advocacy movement, self-advocacy and systems change, supporting self-advocates with information, and self-advocates and advocates working together for change. This bulletin includes brief annotations of a number of video and print resources.

TITLE: The beliefs, values, and principles of self-advocacy

AUTHOR: Inclusion International

PUBLICATION INFORMATION: 1996

Cambridge, MA: Brookline Books.

Inclusion International (formerly The International League of Societies for Persons with Mental Handicap) held it first meeting of its committee on self-advocacy in June of 1993. This booklet was prepared by the committee members, with the help of their support persons, at this meeting. The booklet describes the beliefs and values (e.g., "being a person first") and the principles (e.g., "empowerment" and "equal opportunity") of the committee in a manner that can be understood by all. Also included in the booklet are descriptions of self-advocacy itself, support, the role of the support person, empowerment, and institutions. A final section is composed of interesting stories of "good practice from throughout the world."

TITLE: Effective self advocacy--Empowering people with disabilities to speak for themselves

AUTHOR: Institute on Community Integration

PUBLICATION INFORMATION: 1990

Minneapolis: Institute on Community Integration, University of Minnesota.

This report is a record of discussions during the workshop, "Assisting People with Developmental Disabilities to Speak Effectively for Themselves," held in 1990, at the 114th Annual Conference of the American Association on Mental Retardation. Specifically, the report contains comments made by the workshop participants when sharing their experiences with regard to three main questions. Namely, "what works to help people speak for themselves to change their own lives," "what works to help people speak out to change conditions for all people with disabilities," and "what will strengthen self-advocacy."

TITLE: Self-determination and trust: My experiences and thoughts

AUTHOR: Kennedy, M. J.

PUBLICATION INFORMATION: 1996

In D.J. Sands & M.L. Wehmeyer (Eds.), Self-determination across the life span (pp. 37-50). Baltimore: Paul H. Brookes Publishing Co.

Michael Kennedy, a long-time self-advocate, begins this chapter with a description of his definition of self-determination. "I think it is different for each person...Self-determination for me is knowing that there are resources out there than I can use to educate myself about things that will enhance my growth or independence...I believe that self-determination is a process." Subsequent sections of the chapter discuss issues such as: the importance of trusting relationships; how life changes can support self-determination, and suggestions for creating service systems that support self-determination.

TITLE: Count us in: Growing up with Down syndrome

AUTHORS: Kingsley, J., & Levitz, M.

PUBLICATION INFORMATION: 1994

Harcourt Brace Trade Division
525 B Street, Suite 1900
San Diego, CA 92101-4495

Most people would see Jason Kingsley and Mitchell Levitz simply as two young men with a disability. Count us in is based on more than fifty conversations with Jason and Mitchell and it is from these conversations that it became apparent that these two young men are much more than how they would typically be seen. Jason and Mitchell tell us why they wrote the book: to tell the "Successfully Story of Having Down Syndrome." They also tell us who they are; their friendship (both acted on Sesame Street as children); having a disability -- "there's more to it than I expected"; school experiences; having fun; girls and sex; marriage and children; the important people in their lives; their beliefs; traditions, loss, and grief they have experienced; their views on politics and world affairs; becoming independent, also known as "get off my back please!"; and their plans for the future. This book can be aptly summarized by Jason's words: "Give a baby with a disability a chance to grow a full life. To experience a half-full glass instead of half-empty glass. And think of your abilities, not your disabilities."

TITLE: The self-advocacy movement by people with developmental disabilities: A demographic study and directory of self-advocacy groups in the United States

AUTHOR: Longhurst, N.A.

PUBLICATION INFORMATION: 1994

American Association on Mental Retardation
(in cooperation with People First of Illinois and the Illinois University Affiliated Program in Developmental Disabilities)

American Association on Mental Retardation
444 North Capitol Street, N.W., Suite 846
Washington, DC 20001-1570

There are two components in this book: the results of a national demographic study of self-advocacy groups in the United States and a current directory of active self-advocacy groups organized on a state-by-state basis. Discussion of the survey results includes information on issues such as self-advocacy growth and development; group meeting locations; membership; activities; and the future of self-advocacy.

TITLE: Changing ourselves and our community: Report of a leadership development process with a self-help group in mental health

AUTHOR: Lord, J.

PUBLICATION INFORMATION: 1983

Family and Friends
Mental Health/Waterloo Region
179 King Street, South
Waterloo, ON N2J 1P7
CANADA
and
Centre for Research and Education
in the Human Services
P.O. Box 3036, Station C
Kitchener, ON N2G 4R5
CANADA

That leadership is important in self-help groups is undeniable. This book is an attempt to document a process of change for any self-help group. The purpose of this report is to highlight the unique nature of the leadership development process with a self-help group in mental health and also to raise questions, outline resources and suggest ideas useful to other groups concerned about change. Care has been taken to highlight that this is a "specific process" from which a linkage to "general principles" and issues can be made.

The report deals with the purpose of having self-help groups and the importance of creating a context where members can gain skills and knowledge and expand people's awareness of values, strategies and processes which would be helpful in impacting on mental health issues. There are also sessions included where members can be involved in planning and implementation through role playing, sharing and examining individual needs. Further, this book explores the process of change in the group and in the community in terms of identifying issues that need resolving and utilizing problem solving skills to address these issues.

TITLE: Lives in transition: The process of personal empowerment

AUTHOR: Lord, J.

PUBLICATION INFORMATION: 1991

Centre for Research & Education in Human Services
P.O. Box 3036, Station C
Kitchener, ON N2G 4R5
CANADA

This study of personal empowerment examined the lives of individuals with disabilities in their efforts to increase their participation and to gain more control of their lives. The experiences of the people studied illustrate that empowerment is unique to each individual and his or her context. The book begins with some discussion about defining empowerment and about the role of powerlessness in people's lives. Following chapters discuss issues related to empowerment, such as: gaining awareness, support from others, the role of resources and services, and the role of participation in empowerment.

TITLE: Making a move: Advice from People First members about helping people move out of institutions and nursing homes

AUTHORS: Lyle, O'Brien, C., & O'Brien, J.

PUBLICATION INFORMATION: 1990

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

"In 1990 almost 800 [were to] begin moving from state institutions and nursing homes into community living arrangements like intensive tenant support, tenant support, adult family homes, and group homes." In March of this same year the authors of this paper met with members of People First Chapters of Pierce and Thurston Counties to facilitate a workshop on how People First members could help the people who were leaving the institutions and nursing homes. This monograph is a summary, in their own words, of the advice that self-advocates have for those being moved. Included are the thoughts of People First members on questions such as: "why do you want me to move," "what will my parents think," "what about the people I am leaving behind," "will the place I am moving to be all right for me and if not what can I do about this," "what about money," "what will I do during the day," "how will I learn what I need to, to look out for myself," and "will I still get help as long as I need to?" Following the discussion of these questions, a list of nine ways in which People First could help those leaving institutions and nursing homes were decided upon, including the reaching out of People First to these individuals.

TITLE: Whatever you decide

AUTHOR: Mohr, J.

PUBLICATION INFORMATION: 1983

Available from author:
Jennifer Mohr Johnson
238 Hampton Drive
Venice, CA 90291

Decision making is one issue that needs to be addressed when organizing a self-help group. This book is an example in this endeavor, in that it helps consumers be better prepared in the practice of decision making. This book is aimed at staff, educators and advocates and is geared to meet the needs of people at differing levels of comprehension.

The book first addresses the issue of the importance of teaching decision making skills. It also offers suggestions for forming groups, and various ways of improving group dynamics. Suggestions on how to choose an advocate and lead group discussions are also offered. A number of sample lessons pertaining to each topic are offered. This proves a good book for both advocates and self-advocates in the field.

TITLE: What do members want from People First?

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1991

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

Based on the premise that People First leaders will better serve People First members if they know what these members want from the group, in May of 1991 the authors led a workshop with 50 Washington members to discuss the wants of members. This monograph is a summary of the wants of members from the group itself and from its leaders. Discussions that took place during the workshop centered around topics such as: reasons for which people join People First, problems being faced by the group and in the personal lives of its members, addressing of members' concerns by People First, ways in which branches can help local chapters, and questions that members can ask their People First chapter.

TITLE: Surviving in the system: Mental retardation and the retarding environment

AUTHOR: People First of California

PUBLICATION INFORMATION: 1984

State Council on Developmental Disabilities
1507 21st Street, Room 320
Sacramento, CA 95816

In 1983, People First of California contracted with the California State Council on Developmental Disabilities to assess unmet service needs of people with developmental disabilities. The contract also asked for ideas on the best ways to get people with developmental disabilities to talk about their needs, and finally, for People First to develop a model for helping people with developmental disabilities become self advocates and learn how to form self-advocacy organizations.

This report is a result of work for that contract. The first section discusses results of the unmet needs assessment. Part 2 describes a self-advocacy organization and training model. The report concludes with a section containing a summary of recommendations on a broad range of issues for the service system: the state hospital

system, community-based services, services to families, vocational assessment and job training and support, self-interests of consumers, and organizing and training for self-advocacy.

TITLE: A chance to be made whole: People First members being friends to tear down institution walls

AUTHORS: People First of Tennessee & O'Brien, J.

PUBLICATION INFORMATION: 1997

Nashville, TN: People First of Tennessee.
(Available from the Center on Human Policy)

This monograph describes the efforts of People First of Tennessee to assist people who live in institutions. Because they fought in court for people in institutions, the state has agreed that people will now get the services they need in their communities. One of the ways they assisted was by acting as what lawyers call "next friends" for people in institutions. A "next friend" is somebody who gets a U.S. Federal Judge's attention for people who need the Judge to protect their rights but cannot speak for themselves and have no family willing or able to speak up for them. This manual includes many specific strategies they used as "next friends," as well as many reflections on the barriers that institutions create and ways of breaking through those barriers.

TITLE: Speaking up and speaking out: An international self-advocacy movement

AUTHORS: People First of Washington & Self-Advocacy Project, Rehabilitation Research and Training Center, University of Oregon

PUBLICATION INFORMATION: 1985

Ednick Communications
P.O. Box 3612
Portland, OR 97208

This self-advocacy booklet, perhaps the best resource on the various aspects of self-advocacy, is written for people with disabilities who have an interest in organizing or becoming part of a movement which advocates for their own rights and services. The roles of self-advocates and their advisors are clearly delineated in the booklet, but at the same time there is a recognition that each self-advocacy group will be unique.

The format of the booklet covers the planning and events of an international self-advocacy conference which was held by a group called People First (of Washington State). This group shares their experiences with words and pictures, providing a knowledge base for future self-advocates. Included throughout the volume are personal excerpts on people's thoughts and activities. The chapters cover basic issues such as describing self-advocacy, starting and supporting a local group, expectations about advisors, learning about self-advocacy, evaluating services, starting and supporting a state/province-wide organization, and other critical issues. An excellent resource.

TITLE: Self-determination

AUTHOR: Perske, R. (Ed.)

PUBLICATION INFORMATION: 1989

Minneapolis: Institute on Community Integration, University of Minnesota.

This is a summary of the proceedings of a national conference on self-determination to which sixty people were invited by the Office of Special Education and Rehabilitative Services, U.S. Department of Education. Over half the planners have disabilities of one kind or another. This was a first: people with disabilities, parents, and close supporters being asked to draft specific recommendations for federal officials regarding future directions for people with disabilities. This booklet presents their recommendations, some viewpoints of people at the meeting, and each of the keynote presentations.

TITLE: How we lived and grew together: An interstate seminar on self-advocacy for persons with developmental disabilities

AUTHORS: Perske, R., & Williams, R.

PUBLICATION INFORMATION: 1984

InterServ
Clarence York, President
39 East 51st Street
New York, NY 10022

This is a report on the proceedings of a conference on self-advocacy for people with developmental disabilities. Some of the topics dealt with in this conference were the nature of meaningful work and participation in community activities, consumer empowerment and the effects of attitudes of the community and labeling by professionals of people with developmental disabilities. The booklet has quotes from several government officials as well as from many program participants.

TITLE: Self-determination across the life span

AUTHORS: Sands, D. J., & Wehmeyer, M. L. (Eds.)

PUBLICATION INFORMATION: 1996

Baltimore: Paul H. Brookes Publishing Co.

This volume provides comprehensive discussion of issues related to self-determination. The editors begin with a discussion of the complexities of what is meant by self-determination. They state, "There exists a mistaken belief on the part of some that by promoting self-determination we are, in fact, elevating individual needs and goals over the needs and goals of a collective family or community. A second misinterpretation is the self-determination means absolute control by the individual." This book contains 15 chapters, written by adults with disabilities, parents of children with disabilities, and professionals, addressing self-determination. Chapters in Section I focus on definitional, theoretical, and policy issues, while chapters in Section II contain information and resources oriented toward practitioners.

TITLE: Open the doors - The nuts and bolts of building supports for each other

AUTHOR: Self Advocates Becoming Empowered

PUBLICATION INFORMATION: 1996

Available from:
Tulsa Arc
16 East 16th Street, Suite 405
Tulsa, OK 74119-4447

In the Winter of 1995, the national organization of Self Advocates Becoming Empowered (SABE) conducted a survey asking state advocacy groups to share the accomplishments and activities that helped them to build supports for each other. Specifically, SABE wished to know "how self-advocates are helping each other open

doors within the areas of community, housing, work and relationships." This book is a result of their survey and tells the story of the meaningful contributions that self-advocacy groups are making throughout the United States.

TITLE: Self Advocates Becoming Empowered: The birth of a national organization in the U.S.

AUTHORS: Shoultz, B., & Ward, N.

PUBLICATION INFORMATION: 1996

In G. Dybwad & H.A. Bersani, Jr. (Eds.), New voices: Self-advocacy by people with disabilities (pp. 217-234). Cambridge, MA: Brookline Books.

This chapter describes the evolution of a national self-advocacy organization, Self Advocates Becoming Empowered, from the perspective of one author, who has been involved as an advisor, and the second author, who has been involved as an organizer. It provides information about events and developments leading up to the establishment of SABE, as well as specific organizational efforts involved in the creation of SABE itself. Discussion includes logistical issues such as voting and structure, as well as perspectives about what was exciting and frustrating throughout the process. The last section of the chapter reflects on issues and challenges that SABE faces in the near future.

TITLE: People with developmental disabilities speak out on quality of life: A statewide agenda for enhancing the quality of life of people with disabilities

AUTHORS: Vivona, V., & Kaplan, D.

PUBLICATION INFORMATION: 1990, March

World Institute on Disability
510 16th Street
Oakland, CA 94612

This booklet provides a description of the World Institute on Disability's Quality of Life Project, a project that culminated in a series of conferences in which people with developmental disabilities discussed and made recommendations related to four areas: working, living, loving, and playing. Their recommendations are incorporated in the booklet, as are several appendices that would be helpful to those wishing to put on similar conferences.

TITLE: People First of Nebraska: 8 years of accomplishments

AUTHORS: Ward, N., & Shoultz, B.

PUBLICATION INFORMATION: 1996

In G. Dybwad & H.A. Bersani, Jr. (Eds.), New voices: Self-advocacy by people with disabilities (pp. 203-215). Cambridge, MA: Brookline Books.

The authors of this chapter were both highly involved in self-advocacy in Nebraska, one as a staff person/organizer and the other as an advisor. It describes history and background of self-advocacy in the state, organization of chapters and efforts to strengthen chapters, some of the accomplishments of People First of Nebraska, and some of the lessons learned. It would be useful reading for people in other states who are involved in local and statewide self-advocacy efforts.

TITLE: We can speak for ourselves: Self-advocacy for mentally handicapped people

AUTHORS: Williams, P., & Shoultz, B.

PUBLICATION INFORMATION: 1984

Cambridge, MA: Brookline Books.

The fundamental right of speaking for oneself has long been denied to mentally handicapped people, who have usually had decisions made for them about every detail of their lives. They have, in other words, been taught dependence. In recent years, however, the self-advocacy movement has been proving that people who can learn dependence can also learn independence. This book tells the story of People First of Oregon, Project 2 of Nebraska, and similar projects in England where participants have been building the skills necessary to take charge of their own lives. The book offers practical advice and support for parents, human service workers, and others interested in developing self-advocacy for mentally handicapped people. It includes detailed models of existing projects, lists teaching materials, and presents personal accounts by mentally handicapped participants in self-advocacy projects both in the United States and in England. This book is also a valuable resource to sensitize the direct service worker, the administrator, and the public official to the importance of self-advocacy.

TITLE: People first: Leadership and training manual

AUTHOR: Worrell, B.

PUBLICATION INFORMATION: 1988

The G. Allan Roeher Institute
Kinsmen Building, York University
4700 Keele Street
North York, ON M3J 13P
CANADA

This leadership and training manual was written for leaders, members and advisors who are involved in People First, who are involved in self-advocacy, or who are interested in starting a People First group or making their current group "louder and stronger." People First is one of the many self-advocacy organizations; organizations led by persons with disabilities that are helping persons with disabilities learn "to speak up for themselves and to stand up for their rights." The manual itself answers the following questions and discusses the following issues: what self-advocacy is about, how People First can help you, why do we need self-advocacy; the power of a group, organizing for change, helping each member of People First, rights, strengthening your group, advisors, finding a good advisor, and leadership. To support the answering of these questions and discussion of the above issues are a number of illustrations. The voices of persons with disabilities are also strong in this manual. Explanations and examples all come from, and are in the words of, persons with disabilities themselves. This personal emphasis makes the manual clear, effective, and empowering.

2. Advocacy

Of the many books and chapters on advocacy, we concentrate here on materials that can be used by and on behalf of people with all types of disabilities. These materials include personal stories, "nuts and bolts" suggestions, as well as in-depth examinations of laws, governmental programs, and needed improvements.

TITLE: Principles of whistleblowing

AUTHORS: Biklen, D., & Baker, M.

PUBLICATION INFORMATION: 1979

Syracuse, NY: Center on Human Policy, Syracuse University.

This article provides a clear understanding of why whistleblowing needs to occur. It offers guidelines that help prioritize the most effective steps for carrying out this task. It is a tool which could be used to expose illegal, immoral and otherwise wrong practices in human services, business, government and other organizational settings.

TITLE: Rights and reality: An action guide to the rights of people with disabilities in Wisconsin

AUTHORS: Breedlove, L., Franz, J., Froemming, R., Greenley, D., & Marker, J.

PUBLICATION INFORMATION: 1986

Wisconsin Coalition for Advocacy
16 North Carroll, Suite 400
Madison, WI 53703

This manual provides the reader with a basic understanding of state and federal laws which specifically apply to Wisconsin residents who have physical or mental disabilities. It should be helpful to individuals wishing to advocate for their own rights, or the rights of others. It was also written as an informational guide about the rights of people with disabilities. Brief legal citations that are included may make it useful for lawyers.

This manual is based on the three values concepts of maximizing independence, consumerism and the consumer movement, and the normalization principle. It includes chapters on SSI, Medical Assistance, Medicare, Chapter 51, Protective Services, Civil Commitment, Guardianship, Section 504, Rights in Institutions, Vocational Rehabilitation, the Child Welfare System, and several Wisconsin programs of interest to advocates of individualization.

Although the federal entries may be useful to people from other states, this manual is written from Wisconsin's state law perspective. It is a comprehensive and clearly written assessment of their resources and practices, and useful to anyone wishing to understand better some of the innovative Wisconsin programs and structures.

TITLE: The criminal justice system and mental retardation: Defendants and victims

AUTHORS: Conley, R. W., Luckasson, R., & Bouthilet, G.N. (Eds.)

PUBLICATION INFORMATION: 1992

Baltimore: Paul H. Brookes Publishing Co.

This book provides valuable information for advocates, service providers, and legal representatives regarding people with mental retardation and the criminal justice system. Chapter authors, including authorities in legal representation and service provision, offer discussion of the complex issues surrounding people with mental retardation and the criminal justice system, including: recognizing and preventing victimization, providing competent legal representation, determining criminal responsibility, educating for early prevention of criminal activity, assessing competence to stand trial, and designing appropriate (re)habilitation programs.

TITLE: Unraveling the special education maze: An action guide for parents

AUTHOR: Cutler, B. C.

PUBLICATION INFORMATION: 1981

Research Press
2612 North Mattis Avenue
Champaign, IL 61820

As its title suggests, Unraveling the special education maze is a book about how parents can effectively work with and advocate in schools to improve the quality of programming for their children. Barbara Coyne Cutler, a parent, has long been an activist on behalf of children's rights. She brings a wealth of experience and examples to the text.

In addition though, and perhaps more important, this book speaks to the issue of parent attitudes in a manner few other works have come close to accomplishing. Cutler describes how parents feel when they approach schools. She gives us an accounting of "good" and "not so good" ways in which school personnel treat families. This is a book filled with humor, commitment, and lots of food for consciousness raising. This book will be particularly popular with parents and, I suspect, with administrators as well. It has a lot to teach us all.

TITLE: How to organize an effective parent/advocacy group and move bureaucracies
and
How to get services by being assertive

AUTHOR: Des Jardins, C.

PUBLICATION INFORMATION: 1980

Family Resource Center on Disabilities
20 East Jackson Boulevard, Room 900
Chicago, IL 60604

Both of these handbooks serve to guide the reader through advocacy issues. They were specifically written for parents and siblings of children with disabilities, but they are generalizable to any situation that calls for advocacy in order to obtain necessary services.

The handbooks are instructive and deal with the "how to's" of organizing advocacy efforts. They also are written with a strong amount of encouragement to get involved in the issues which face the reader or his/her relative. The tone of these handbooks is that of an assertiveness workshop, and they tend to be oriented toward women who are relatively inexperienced in speaking out for what they believe.

TITLE: The Americans with Disabilities Act: A guide for people with disabilities, their families, and advocates

AUTHORS: Goldberg, D., & Goldberg, M.

PUBLICATION INFORMATION: 1993

PACER Center, Inc.
4826 Chicago Avenue, South
Minneapolis, MN 55417-1098

This guide is designed to help people with disabilities, their families, and advocates learn about the ADA and how it can aid in the prevention of discrimination against people with disabilities. The guide covers the ADA definition of a disability as well as the five Titles under the act. Coverage is done in a manner that is easily comprehensible and through the use of many fun sketches and stories. Lists of responsible agencies, ADA resources, and parent training and information centers are also included at the end of this guide.

TITLE: Disability rights guide

AUTHOR: Goldman, C. D.

PUBLICATION INFORMATION: 1987

Media Publishing
2440 "O" Street, Suite 202
Lincoln, NE 68510-1125

This book is intended for use by all persons who deal with the important human issues confronted by persons with physical or mental limitations. Chapter One focuses on Attitudinal Barriers and demystifies some of the generally accepted misconceptions regarding people with disabilities (e.g., disability is inability). Outlined in the following chapters are employment, accessibility, housing, education, and transportation. In reference to each of these issues, state, federal, and local laws are highlighted and practical solutions to these problems are suggested in each chapter.

Also included are three appendixes: Appendix I: State by State Guide: Laws & Contacts; Appendix II: Federal Contacts; and Appendix III: A.I.D.S.

TITLE: Implementing the Americans with Disabilities Act: Rights and responsibilities of all Americans

AUTHORS: Gostin, L. O., & Beyer, H. A. (Eds.)

PUBLICATION INFORMATION: 1993

Baltimore: Paul H. Brookes Publishing Co.

Written by law and disability experts--many of whom were instrumental in constructing the ADA--this book is an excellent resource. Chapters in the first section cover the history and legal framework that formed the bases of the ADA. The second section describes key provisions of the ADA. Finally, the third section discusses related issues, such as health care, genetic discrimination, mental and psychiatric disorders and the ADA, the ADA in international perspective, and a personal perspective on disability policy.

TITLE: ACTION: A manual to help you organize

AUTHOR: Governor's Planning Council on Developmental Disabilities

PUBLICATION INFORMATION: 1989

Governor's Planning Council on Developmental Disabilities
Minnesota State Planning Agency
300 Centennial Building
658 Cedar Street
St. Paul, MN 55155

This handbook is designed to offer some common-sense tactics for consumer advocates to use in achieving their goals. It explains the strength gained by organizing and knowing your allies. Listed are specific sources of background material and where to obtain them. It explains writing techniques and provides a sample questionnaire, and has copies of petitions and letters to aid in canvassing and developing new support for your group. There is much valuable information on how to meet in person and on public speaking. This clearly written manual offers many suggestions and would prove an asset to any group or individual desiring to organize effectively.

Copies are available free of charge by contacting the above address.

TITLE: Rights and advocacy for retarded people

AUTHOR: Herr, S. S.

PUBLICATION INFORMATION: 1983

Lexington Books
D.C. Heath and Company
Lexington, MA 02173

This text chronicles judicial activity during the second half of the twentieth century. It is a comprehensive review that reflects on the multitude of legal developments from a variety of perspectives--historical, international, and policy-oriented--that help explain the growing awareness of the need to enforce human and legal rights for individuals with a mental disability.

It examines the legal frameworks that perpetuated the residential segregation of people with mental retardation. It considers to what extent lawmakers can undo this history of segregation and delineates the legal directions and safeguards that offer a brighter future. Changes in due process now give clients and their representatives the right to object to care and treatment received. Though the rights to care, habilitation, and education exist, the means of their delivery are inchoate. This is why legal advocates must continue to gain support for their complex agenda: diligent monitoring of resettlement efforts, a wide range of choices of living arrangements and services of intimate scale and high quality, and more comprehensive legal reform.

The author strongly speaks out in favor of the advocacy movement for those who are too young, too incapacitated or too vulnerable to act alone. He defines and discusses the many types of advocacy that are available to assure these individuals' rights.

TITLE: Organizing--A guide for grassroots leaders

AUTHOR: Kahn, S.

PUBLICATION INFORMATION: 1982

McGraw-Hill Book Company
1221 Avenue of the Americas
New York, NY 10020

This book is a comprehensive, clearly written resource that explains the benefits of organizing as well as where and how to start. It offers insight into building organizations, identifying constituencies, selecting leaders and encouraging membership. It provides specific tactics for carrying out the strategies that your organization develops based on the goals of the group. Also addressed are media contacts and the advantages and disadvantages of including the media in various communication strategies of the organization. Money management and coalition building are two other areas that the book highlights.

This reference tool is valuable to both individuals who want to start a new group and leaders of established organizations.

TITLE: Training exercises for human rights committee volunteers

AUTHORS: Laski, F., & Piccoli, M.

PUBLICATION INFORMATION: 1984

Community Human Rights Committee Project
Developmental Disabilities Center
Temple University
Ritter Hall Annex, 9th floor
Philadelphia, PA 19122

This manual is based on training programs conducted by the Human Rights Committee Project Staff. It is directed at volunteers who have already received substantive training or who have experience working in human services for people with developmental disabilities.

A human rights committee generally oversees the behavior management and medication programs of an agency. In this role, it is a watchdog that monitors agency practices and ensures individuals' rights.

This manual discusses some specific issues of individual rights that surfaced during their brainstorming session. After a discussion of Behavior Modification and Policy issues, there are exercises in medications policy and individual complaint hearings.

Although this is geared toward people of some experience, there is a wealth of information presented in a clearly organized structure. It provides an understanding of the role and activities of human rights committees. Also included are various copies of letter styles, and reports and forms used in records of individuals.

TITLE: Toward independence: An assessment of federal laws and programs affecting persons with disabilities--with legislative recommendations

AUTHOR: National Council on the Handicapped

PUBLICATION INFORMATION: 1986

National Council on the Handicapped
800 Independence Avenue, S.W., Suite 814
Washington, DC 20591

Although the nation's goals regarding citizens with disabilities have often been stated, Federal programs and laws have often deviated from the paths leading to these goals. This report results from Congress' direction to the National Council on the

Handicapped to assess Federal programs to determine the extent to which they achieve the following: a) provide incentives or disincentives to the establishment of community-based services for individuals with disabilities; b) promote the full integration of such individuals in the community, in the schools, and in the workplace; and c) contribute to the independence and dignity of such individuals.

Contained within this report are some very revealing statistics about the ten major topic areas isolated for assessment. These topic areas are: Equal Opportunity Laws, Employment, Disincentives to Work Under Social Security Laws, Prevention of Disabilities, Transportation, Community-Based Services for Independent Living, Housing, Educating Children with Disabilities, Coordination, and Personal Assistance: Attendant Services, Readers, Interpreters.

The major conclusions and legislative recommendations of the Council regarding these areas are included in this report.

TITLE: Mental disabilities and Americans with Disabilities Act: A practitioner's guide to employment, insurance, treatment, public access, and housing

AUTHOR: Parry, J. (Ed.)

PUBLICATION INFORMATION: 1994

American Bar Association's Committee on
Mental and Physical Disability Law
1800 M Street, N.W., Suite 200
Washington, DC 20036-5886

Persons labeled with mental retardation or developmental disabilities are often cited as the overlooked group in the ADA legislation. Yet, "the ADA has different consequences in many important areas for persons with mental, developmental, learning, and cognitive disabilities than for persons with physical disabilities. Some of these differences may result in fewer protections for individuals who have mental impairments." This guide is designed for practitioners who represent persons with disabilities, such as lawyers and other advocates. Issues discussed include: the act itself, enforcement mechanisms, mental disability coverage, key legal concepts, the hiring process, work placement accommodations, health insurance and worker's compensation, employer-sponsored health benefits, licenses, credentials and Bar admissions, medical licensure, treatment issues--prescriptions, side effects, right to refusal of treatment--attendant care, courthouse access, and housing. Also included in the appendices are descriptions of: mental disability terminology, prior federal laws, summaries of major case decisions, and a list of national resources.

TITLE: Deadly innocence?

AUTHOR: Perske, R.

PUBLICATION INFORMATION: 1995

Abingdon Press
201 Eighth Avenue, South
Nashville, TN 37203

In this book, Perske traces the life of Joe Arridy from birth to gas chamber (1915-1939). Arridy, a Syrian-American, had been kicked out of elementary school, labeled "feebleminded," and placed in a "state home for mental defectives." During the Great Depression, when thousands of people traveled by "hopping freights," he walked away from the institution and became an avid boxcar rider until a sheriff in Cheyenne, Wyoming, led him to confess to the vicious rape and ax murder of a teenager in Pueblo. Arridy was tried and convinced in Pueblo under strange circumstances. He was executed in Canon City even though Warden Roy Best worked undercover to stop the execution. This powerful historical account is relevant, as well, to the current experiences of people labeled mentally retarded in the criminal justice system.

TITLE: Unequal justice?: What can happen when persons with retardation or other developmental disabilities encounter the criminal justice system

AUTHOR: Perske, R.

PUBLICATION INFORMATION: 1991

Abingdon Press
201 Eighth Avenue, South
Nashville, TN 37203

This book is a compilation of accounts of encounters of people with developmental disabilities with the criminal justice system. Some become caught up and hidden away in the criminal justice system for years; others are executed. Perske wrote this book in order to shed light on such situations. He wonders, whether guilty or innocent, did the system treat that person as other citizens are treated when charged with the same crime? Did that person receive equal justice?

TITLE: Negotiation: A tool for change

AUTHOR: Taylor, S. J.

PUBLICATION INFORMATION: 1979

Syracuse, NY: Center on Human Policy, Syracuse University.

This paper is designed to enable consumers, parents and advocates to negotiate effectively, whether it is for short- or long-term change. It concisely outlines steps for general negotiation preparation such as knowing when to negotiate, obtaining backing by a consumer or interest group, setting up the negotiation, targeting agency heads/persons with authority, organizing meetings, forming a negotiating team and preparation for the actual negotiation. It also lists strategies for effective negotiation and follow-up techniques.

TITLE: The ADA mandate for social change

AUTHOR: Wehman, P. (Ed.)

PUBLICATION INFORMATION: 1993

Baltimore: Paul H. Brookes Publishing Co.

The Americans with Disabilities Act (ADA) is generally cited as the most important advancement in the history of disability rights. Acknowledging that persons with disabilities--43 million Americans--have, and continue to, experience discrimination in areas such as employment, housing, and public accommodations, the purpose of the ADA is both to prevent and to begin to ameliorate discrimination against such persons. Yet, when the full impact of the ADA is felt, "how will society be affected and how will it respond?"

This edited book addresses these very questions through analyses of the ADA and offerings of valuable insights for more complete understandings of societal implications of the legislation. Discussed issues include: redefining equality through the ADA, quality of life and consumer choice, employment--both supported and open, and reasonable accommodation.

TITLE: Citizen advocacy and protective services for the impaired and handicapped

AUTHORS: Wolfensberger, W., & Zauha, H. (Eds.)

PUBLICATION INFORMATION: 1973

Toronto: National Institute on Mental Retardation

TITLE: CAPE: Standards for citizen advocacy program evaluation

AUTHORS: O'Brien, J., & Wolfensberger, W.

PUBLICATION INFORMATION: 1980

Toronto: The Canadian Association for the Mentally Retarded

TITLE: Learning from citizen advocacy programs

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1987

Atlanta: Georgia Advocacy Office

As a concept put into practice, citizen advocacy (CA), formulated by Dr. Wolf Wolfensberger, was part of a larger schema that delineated advocacy and protective services needed by people with mental retardation. These services were designed to provide the necessary protection for handicapped individuals who were unable to represent themselves and had no family or friends to safeguard their interests. CA was an attempt to respond to the parents' question, "What will happen to my disabled son or daughter when I'm gone?" Wolfensberger defined CA as "...a mature, competent citizen volunteer representing, as if they were his own, the interests of another citizen who is impaired in his instrumental competency, or who has major expressive needs which are unmet and which are likely to remain unmet without special intervention" (Wolfensberger & Zauha, 1983).

CAPE (O'Brien & Wolfensberger, 1980) is an evaluation tool designed to compare the practices found in a CA program to the standards set by the definition and principles of citizen advocacy. CAPE is made up of 36 ratings which examine the

efforts of the staff and board to recruit and introduce people who require protection, practical assistance, and/or friendship (proteges, partners) to capable citizens who attempt to address those needs (advocates).

O'Brien's manual (1987) provides an expanded definition and rearticulates the principles of CA. This manual reflects the experiences of people in the United States, Canada, England, and Australia trying to put Wolfensberger's theory into practice. Learning from citizen advocacy programs is a collection of questions, activities, and resources about CA. While external evaluation teams may use the manual (O'Brien suggests the possibility of doing so in conjunction with the CAPE tool), boards and staff of CA offices may also use it to review their own work.

Despite the different purposes of these publications, all of the authors assume that at least some typical citizens will choose to become involved in a personal, one-to-one relationship with someone who is devalued by the society at large. Those interested in the concept of citizen advocacy are encouraged to read all three of these publications.

TITLE: You've got a friend

AUTHOR: Worth, P.

PUBLICATION INFORMATION:

In The pursuit of leisure: Enriching the lives of people who have a disability.

The G. Allan Roeher Institute
York University, Kinsmen Building
4700 Keele Street
North York, ON M3J 1P3
CANADA

This chapter comes from a book entitled The pursuit of leisure. The honesty of Pat Worth's account of how people with disabilities are trapped without the support of advocates is moving. It is a truly personal perspective on the need for advocates to aid persons with disabilities in their quest for freedom and choice.

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3. Families

Over the past 40 years, the families of children and adults with disabilities have been a tremendously important force for positive changes in services for people with disabilities. In the past decade, the research and the materials about families have "caught up" with where so many families have always been. The books reviewed in this section are positive about and helpful to families who have one or more family members with disabilities.

TITLE: Life as we know it: A father, a family, and an exceptional child

AUTHOR: Bérubé, M.

PUBLICATION INFORMATION: 1996

Random House
400 Hahn Road
Westminster, MD 21107

This remarkable book is a father's story of the life of his 4-year-old son James, who has Down syndrome. It is far more than just a personal memoir of his son's birth and young life. In following the developmental stages, social experiences, and involvement with social services that James passes through, Bérubé explores their social implications, including such topics as I.Q. testing, the politics of education, disability law, social services, health care, and entitlements. Implicit in these discussions are not just his own family's experiences in these realms, but also concepts such as social justice, what it means to be human, and what kind of society we value and by what means we determine it.

TITLE: A difference in the family: Life with a disabled child

AUTHOR: Featherstone, H.

PUBLICATION INFORMATION: 1980

New York: Basic Books, Inc.

Available from:
Penguin Books
40 West 23rd Street
New York, NY 10010

Having a severely handicapped child, says the author, makes a difference in the family. At first, willy-nilly, the disabled child is a dominant motif. But in time, the family becomes accustomed to the situation and gradually returns to the mainstream. Born out of her own experience as the mother of a multiply handicapped boy, this book is about how it feels to belong to a family with a disabled child.

The book uses three sources of information: the author's own experience, personal interviews conducted by the author with other families, and a well-researched body of literature written by parents on their experiences. Chapters deal individually with fear, anger, loneliness, guilt and self-doubt, and acceptance, as the book describes the emotional stages the family goes through as it learns to live with a disabled child. Other concerns are marital stress, siblings, and giving and getting help. A particularly useful resource for professionals working with families, the book provides an insightful analysis into the many ways the presence of a child with disabilities changes the structure of the family.

TITLE: The power of positive linking: How families can empower people who have a mental handicap through mutual support groups

AUTHOR: The G. Allan Roeher Institute

PUBLICATION INFORMATION: 1989

The G. Allan Roeher Institute
Kinsmen Building, York University
4700 Keele Street
North York, ON M3J 1P3
CANADA

This study documents the evolution of five support groups across Canada. Each group was made up of families with a disabled member who came together during times of crisis and/or trying to identify more opportunities for their family members with disabilities. Through in-depth interviews, the experiences of these mutual support groups were collected. The study describes how the five support groups were established, the meaning, process, and goals of "support," and the internal functioning of the groups over time. How the support groups established ties to other groups and agencies in order to obtain needed resources to meet their goals is also discussed.

While the title suggests otherwise, this study really explores the empowerment of the families through the mutual support groups.

TITLE: Meeting the challenge of disability or chronic illness - A family guide

AUTHORS: Goldfarb, L. A., Brotherson, M. J., Summers, J. A., & Turnbull, A. P.

PUBLICATION INFORMATION: 1986

Baltimore: Paul H. Brookes Publishing Co.

This book is an extremely unique and valuable tool, written for all families experiencing any type of situation involving care of an ill or disabled family member. It is also an important resource for professionals working with families.

Filled with practical worksheets, activities and exercises, it provides information and techniques for family members to utilize in coping with their particular situation.

Part I, "Taking Stock," discusses methods of coping, relying on one's value system, and various types of social and professional support. Part II, "Problem Solving," deals with family communication, problem definition, brainstorming for solutions, evaluation of alternatives, and action toward solving problems. The authors also include an Appendix of Resources, which contains a number of bibliographies on various subjects and a list of support organizations.

TITLE: Couples with intellectual disabilities talk about living and loving

AUTHOR: Melberg Schwier, K.

PUBLICATION INFORMATION: 1994

Woodbine House
5615 Fishers Lane
Rockville, MD 20852

"Every person deserves the chance to love and to be loved, regardless of their mental or physical disability." Yet, human services for the most part fail to extend this need to include persons with disabilities. Either it is assumed that these persons do not want or cannot benefit from intimate relationships, or we are simply too embarrassed to discuss the matter. In this book we enter into conversation with 15 couples, of varying ages and nationalities, who have found meaningful intimate relationships. We learn about "earnest beginnings"; marriage; parenthood--a form of family about which we often forget; long-term couples; and, most of all, that persons with disabilities can, and do, have meaningful intimate relationships with other persons.

TITLE: As up we grew with Barbara

AUTHOR: Moise, L. E.

PUBLICATION INFORMATION: 1980

TASH
29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204

This book belongs to an important genre of first-person accounts by parents who, after becoming activists in the parent movement, wrote about their experiences. Many of these parents, who are now in their sixties or seventies, paved the way for today's strong parent movement. This book is a very personal description of the Moise family's life with Barbara, the child with the disability, and of the family's suffering and growth as they encountered inexpert and insensitive professionals, inadequate services, societal rejection, and the realization that these were not the family's fault but instead the result of a social injustice that could be resisted. This book describes Barbara's growth, but it also traces the author's transformation from parent to activist, and discusses many issues rising out of the transformation. (There are many books that belong to this genre, and that will not be annotated here for space reasons. Feel free, however, to write or call the Center on Human Policy for other titles.)

TITLE: Letting go, moving on: A parent's thoughts

AUTHOR: Moore, C.

PUBLICATION INFORMATION: 1993

In J. A. Racino, P. Walker, S. O'Connor, & S. J. Taylor (Eds.), Housing, support, and community: Choices and strategies for adults with disabilities (pp. 189-204). Baltimore: Paul H. Brookes Publishing Co.

Cory Moore was a professional in the developmental disability service system as well as a parent of child with a disability. She wrote this chapter from her parent perspective. It describes the experience of supporting her daughter to move away from home; first to live in a group home and eventually to have one of her own. Many parents will find the chapter helpful as she relates the feelings and dilemmas she experienced and shared with other parents in this process. She discusses the limitations of group home living and the advantages and risks of home ownership.

TITLE: More than what they bargained for: The meaning of support to families

AUTHOR: O'Connor, S.

PUBLICATION INFORMATION: 1995

In S. J. Taylor, R. Bogdan, & Z. M. Lutfiyya (Eds.), The variety of community experience: Qualitative studies of family and community life (pp. 193-210). Baltimore: Paul H. Brookes Publishing Co.

Each family is unique. They come from different racial, ethnic, and socioeconomic backgrounds. Yet, in family support services, disability usually overrides these other differences. This chapter looks at four families, from different backgrounds, in terms of (1) their definitions of their needs, including family versus the individual, concrete, and practical needs; (2) change from the private family to the public client role; and (3) cost of help to families. O'Connor concludes by reminding professionals must get to know families and appreciate them for who they are in terms of their values, fears and concerns.

TITLE: We're all one family: The positive construction of people with disabilities by family members

AUTHOR: O'Connor, S.

PUBLICATION INFORMATION: 1995

In S. J. Taylor, R. Bogdan, & Z. M. Lutfiyya (Eds.), The variety of community experience: Qualitative studies of family and community life (pp. 193-210). Baltimore: Paul H. Brookes Publishing Co.

Traditionally, families of children with disabilities were described in terms of negatives--stress and grieving. Reduction of this negative focus can occur by, instead, viewing families in terms of relationships of acceptance. Accepting relationships view individuals not in terms of differences, but, simply, as family members. This chapter tells the story of the Henry family. The Henry's youngest son, Chas, has been labeled as autistic. However, the Henrys see Chas according to the same beliefs, values, and rules that they use for their other sons. A relationship of acceptance allows the Henrys to see Chas's `autistic tendencies,' such as, flapping his hands and waking up at night, as signs of excitement and inherited family habits, respectively. Through this family, O'Connor helps readers to understand the nature of long ignored, familial acceptance relationships.

TITLE: Hope for the families: New directions for parents of persons with retardation or other disabilities

AUTHOR: Perske, R. (Illustrated by M. Perske)

PUBLICATION INFORMATION: 1981

Abingdon Press
201 Eighth Avenue, South
P.O. Box 801
Nashville, TN 37202

As the author says, "this book is for families who are trying to turn a tough situation into a rich experience." This is one of THE books for families in which one of the members has a disability. In 28 brief up-beat chapters, the author confronts and exorcises the ghosts which our culture imposes on disabled persons and their families. He shows many ways parents and families can overcome their fears and inhibitions. Some of the wide-ranging topics discussed include: changing world views, theology, human dignity, sexual development, family systems, and opening opportunities for persons with retardation and other disabilities. To clarify his meaning, draw out his implications and encourage discussion, the author concludes most chapters with mini-"home"-work assignments entitled "Consider these options." The marvelous illustrations re-double the impact of this impressive little book.

TITLE: Parent to parent

AUTHOR: Pizzo, P.

PUBLICATION INFORMATION: 1983

Beacon Press
25 Beacon Street
Boston, MA 02108

This book is about parent self-help and advocacy, and discusses the ways in which parents facing all sorts of problems, ranging from loss of a child due to drunk driving to abusiveness toward their children to having a child with a disability, have come together to help and get support from parents facing similar problems. The author discusses ways in which people sharing the same experience can empower each other, gives a history of parent activism, discusses and debunks commonly held stereotypes of parents, and gives a myriad of examples of ways parent power has changed laws, services, and attitudes. This book is useful for several reasons--it gives a

history of a number of parent-initiated movements (black single parents, parents of children with disabilities, etc.), showing how the issues they face and the forces to which they have responded may have common sources; it describes women activists in all these movements; and it lists parent self-help and advocacy organizations.

TITLE: Yes! She knows she's here

AUTHOR: Schaefer, N.

PUBLICATION INFORMATION: 1997

Inclusion Press
24 Thome Crescent
Toronto, ON M6H 2S5
CANADA

In 1986, just before her 25th birthday, Catherine moved from her parents' house into her own home. A previous book by her mother, Does she know she's there (to be reissued by Fitzhenry & Whiteside in 1998), documented her life story. This book provides a continuation of that story. It describes the planning and effort that goes into ensuring that she has the necessary paid supports available, as well as the role of family members, housemates, and friends in Catherine's life today. A must read for families as well as professionals.

TITLE: After the tears: Parents talk about raising a child with a disability

AUTHOR: Simons, R.

PUBLICATION INFORMATION: 1987

Harcourt Brace Jovanovich Publishers
1250 Sixth Avenue
San Diego, CA 92101

Like most books that deal with parents' perspectives on disability, this book describes the emotional stages that parents go through on learning of their child's disability. What makes it a book to be recommended is that it also describes how parents have dealt with these stages.

The book is very readable, being slim with short chapters that contain extensive quotes by parents. It legitimizes as being normal the strong emotions of anger and guilt that parents may experience. It accepts that some of the consequences of having a disabled child may have to do with the awkwardness of dealing with marital stress,

relatives, siblings, professionals, and worries about the future. But unlike most other books, this book goes beyond and offers solutions arrived at by parents themselves for those situations most commonly encountered (for examples, architectural barriers, the school system, curious strangers) while recognizing the fact that solutions are not universally applicable and would, of necessity, differ according to the circumstances of each family.

Each chapter closes with simple and practical suggestions and strategies. The last chapter lists some resources on information and referral services, health care, legal aid, advocacy, books, publications, directories and films.

TITLE: Making changes: Family voices on living with disabilities

AUTHORS: Spiegle, J. A., & van den Pol, R. A.

PUBLICATION INFORMATION: 1993

Cambridge, MA: Brookline.

Parents, siblings, and relatives are often ignored in studies of families who have a member with a disability. Making changes give a voice to all members of these families--parents, siblings, and the child with a disability. Spiegle compliments the stories of other families with her own stories of loosing a friend and classmate to a special education class, the daughter of a family friend being institutionalized, and the birth of her daughter Sara--who has Down syndrome. Included are excerpts from Spiegle's diary, in which she talks of both the joys and frustrations of caring for Sara; letters from a close friend--who also has a child with a disability--to Spiegle over a 6-year span; and stories on issues such as, possibilities, diagnosis, acceptance, medication, out-of-home placement and respite care, health care providers, teachers, and provider versus consumer perspectives.

TITLE: Families, professionals, and exceptionality: A special partnership (2nd ed.)

AUTHORS: Turnbull, A. P., & Turnbull, H. R.

PUBLICATION INFORMATION: 1990

Macmillan Publishing Co.
Front & Brown Streets
Riverside, NJ 08075

or

Merrill Publishing Co.
1300 Alum Creek Drive
Columbus, OH 43216

This book, which can be used as a textbook for students training to become professionals, will also be of interest to those who are currently professionals and to family members. It is value-based, in that it identifies six core values about people with disabilities and their families and points out ways throughout the book to incorporate these values into professional practice. This edition emphasizes the application of family-systems theory in professional practice, taking into account the variety and diversity in families and the various life cycle stages families generally pass through.

The chapters explore the historical and current roles of parents, family characteristics, family interaction, family functions, family life cycle, communication skills for professionals, strategies for communication, P.L. 94-142, various aspects of family involvement and legal issues, ways of supporting families and helping them cope, and professional ethics and morals. The book presents positive ways of understanding and working with families, giving many examples and quoting many parents. The points of view of family members in many different situations are presented, so that the reader comes away with a feeling of having met and talked frankly with many parents, siblings, and extended family members. The chapter on ethics and morals is replete with case examples that present moral or ethical conflicts as well as succinct descriptions of sources of moral principles for students to consider. Throughout, the book provides references and data to back up the content, and includes an extensive reference list and two appendices (resources for families and professionals and a guide for gathering family information through discussion) at the end.

TITLE: Parents speak out: Then and now

AUTHORS: Turnbull, H. R., & Turnbull, A. P. (Eds.).

PUBLICATION INFORMATION: 1985

Charles E. Merrill Publishing Co.
1300 Alum Creek Drive
Columbia, OH 43216

This book is a collection of essays by parents (twelve mothers, seven fathers) and a few brothers and sisters of people with disabilities. Many of the authors are seen as leaders in the parent movement, and a number have qualifications as professionals in some aspect of the health or disability field. Some of the essays by professionals reflect on the difference in perspective when one is in the parent role and dealing with the professionals who exercise power over the services one's child receives. Many of the essays are passionate, describing the personal feelings of the authors in parenting a child with disabilities and dealing with societal and professional pressures and prejudices. A classic in the "parent" literature.

TITLE: Disability and the family: A guide to decisions for adulthood

AUTHORS: Turnbull, H. R., Turnbull, A. P., Bronicki, G. J., Summers, J. A., & Roeder-Gordon, C.

PUBLICATION INFORMATION: 1989

Baltimore: Paul H. Brookes Publishing Co.

This book is a planning guide for families who have one or more members with disabilities. It specifically emphasizes the period of transition to adulthood, but can be used by any family wishing to consider alternatives for a disabled family member. The book provides a wealth of help and information for families thinking about the future, such as a "preference checklist" that helps families determine the preferred supports and services their family member will need. There are two chapters on advocacy that encourage parents to speak out vigorously within existing services for what their child needs or to participate in creating new services if existing services are unresponsive.

These two chapters assume that the family members have made explicit their needs and dreams for the person with the disability, and have decided, together with that person, what the future for that person should look like. They also assume that many of the actual services the person and the family may encounter will fall far short of the picture they have created, and that families must find ways of causing change to meet their family member's needs.

4. Acceptance, Relationships, and Community

Almost all people need to feel that they belong and have meaningful relationships with others. Unfortunately, much of the literature reflects a belief that communities and the people in them are unable and unwilling to welcome people with developmental disabilities into their midst. There are studies on loneliness and isolation, courses on the sociology of deviance, and workshops and books on ways of overcoming community resistance.

The materials in this section reflect a more positive way of thinking. They look at accepting relationships and responsive communities, and examine some of the dynamics that underlie these phenomena. They propose changes, not just in "the community," but in ourselves. In what ways have we--service providers, professionals, advocates--created the barriers we talk about? How can we best promote and support caring relationships and community participation? These materials attempt to address these issues at several levels.

TITLE: Enhancing the social inclusion of persons with developmental disabilities

AUTHORS: Abery, B. H., & Fahnestock, M.

PUBLICATION INFORMATION: 1994

In M. F. Hayden & B. H. Abery (Eds.), Challenges for a service system in transition (pp. 83-119). Baltimore: Paul H. Brookes Publishing Co.

The authors stress the importance of a wide variety of types of social relationships in people's lives. The chapter begins with a discussion of the nature of social relationships. It elaborates on issues related to social relationships and networks, including a review of related research. A person-centered approach to the development of social relationships is advocated, with examples and strategies offered.

TITLE: Friendships and community connections between people with and without developmental disabilities

AUTHOR: Amado, A.N. (Ed.)

PUBLICATION INFORMATION: 1993

Baltimore: Paul H. Brookes Publishing Co.

This book contains chapters that discuss a wide variety of critical issues related to friendship and people with developmental disabilities. It is acknowledged that "supporting friendships can be fragile, delicate, magical, and sensitive work. It is not work that easily fits into formalized systems and agency patterns" (p. 373). Authors discuss dilemmas and challenges related to this.

The book is divided into three sections: (1) dimensions of friendships, (2) stories of friendships and (3) strategies for building friendships. Chapters in the first section include an introductory piece by John O'Brien and Connie Lyle O'Brien discussing dimension of friendship, issues of attraction and power, and context of community; loneliness; intimacy and sexual relationships; the gendered context of friendships; and friendships between "staff" and "clients." The second section contains stories of friendship written by people with disabilities, parents, and advocates from within and outside of the service system. Finally, chapters in the third section offer important strategies based upon focused efforts to assist people to form friendships and connections at work, in community associations, and within the community at large.

TITLE: Amistad: Stories of Hispanic children with disabilities and their friendships

AUTHOR: Beach Center on Families and Disability

PUBLICATION INFORMATION: 1997

Beach Center on Families and Disability
3111 Haworth
University of Kansas
Lawrence, KS 66045

This monograph, aimed primarily for families and educators, is the result of a study on friendship that focused on the Hispanic population. The intent was to find examples of "successful" friendships for children who experience significant disability. The stories are presented here, followed by a concluding section outlining "friendship tips" and giving additional resources.

TITLE: The social basis of community care

AUTHOR: Bulmer, M.

PUBLICATION INFORMATION: 1987

Allen & Unwin, Inc.
8 Winchester Place
Winchester, MA 01890

This book analyzes the relationship between ideas about community life and the impact of social policy, demonstrating that, at least in England, there is "a vacuum at the heart of care policy which is likely to lead to ineffective or deteriorating provision of services" (p. ix). Bulmer's analysis is very relevant to North American discussions about community integration of people with disabilities. The book focuses more on informal support or care than on services and service systems, but he looks at both and at the interface between the two types of care in the community. His analysis draws heavily on a variety of research studies conducted in neighborhoods, within groups of families, and in other aspects of community life and is a major contribution to the discussion about community integration.

TITLE: Interdependence: The route to community

AUTHOR: Condeluci, A.

PUBLICATION INFORMATION: 1991

Orlando, FL : Paul M. Deutsch Press, Inc.

The book begins with a discussion of disempowerment--the ways people lose power and are oppressed and stereotyped. This discussion concludes with some lessons about change from the civil rights movement. Chapter 2 describes various paradigms within human services, including the medical, educational, economic, and maintenance paradigms. The next chapter outlines an alternative paradigm--the interdependence paradigm. In summary, the three goals of this paradigm are acceptance, relationships, and opportunity. Chapter 4 details four factors that are key to achieving interdependence: role competency enhancement, supplemental supports, relationship building, and systems advocacy. The fifth chapter focuses on "understanding community." It describes various functions of community, formal and informal dimensions of community, community space issues, communication issues, and learning about community issues.

TITLE: It's about relationships

AUTHOR: Forest, M.

PUBLICATION INFORMATION: 1989

Frontier College Press
35 Jackes Avenue
Toronto, Ontario M4T 1E2
CANADA

This essay is also a chapter in L. Meyer, C. Peck and L. Brown, Critical issues in the lives of people with disabilities (1990), Paul Brookes Publishing Company. It is a personal reflection by Marsha Forest on the many relationships that have enriched her life and the lives of her friends and family members. Interwoven with the personal stories are stories about integrating students with disabilities into regular schools. Forest points out how much we all have to give each other, and how much we miss when people with perceived differences are excluded from schools, neighborhoods, and friendship circles.

TITLE: Everyone here spoke sign language: Hereditary deafness on Martha's Vineyard

AUTHOR: Groce, N. E.

PUBLICATION INFORMATION: 1985

Harvard University Press
79 Garden Street
Cambridge, MA 02138

This ethno-historical study is an excellent portrayal of community life for deaf and hearing individuals of Martha's Vineyard. The reader is presented with the history of how the deafness was brought to the island. The book allows the reader to view the typicality of the lives of Islanders who were deaf, typicality due to the community's acceptance and ability to communicate with them. Groce takes us beyond the confines of medical or social definitions of deviancy and offers evidence that our pre-conceived stereotypes of what a disability may mean are really determined by the social construct we create as a society.

This well-researched book is a must, not only for people interested in the field of disabilities but for anyone trying to struggle with integration into community life. The book is a simple thesis offering a profound message in a wide array of disciplines. It will add thought to issues that will remain unresolved and discussed for a long time to come.

TITLE: Friends: A manual for connecting persons with disabilities and community members

AUTHOR: Human Services Research and Development Center

PUBLICATION INFORMATION:

Human Services Research and Development Center
Minnesota Developmental Disabilities Council
300 Centennial Office Building
658 Cedar Street
St. Paul, MN 55155

This manual grew out of the "Friends" project, a one-year grant project sponsored in 1989-90 by the Human Services Research and Development Center of St. Paul, Minnesota, and funded by the Minnesota Governor's Planning Council on Developmental Disabilities. The purpose of the project was to learn about and develop methods for the staff of residential service agencies to support people with disabilities in establishing friendships and relationships with nondisabled people in their communities and to assist people with disabilities in being more a part of their communities.

Sections of the manual contain information on: planning with people; strategies to facilitate connections; introducing people; providing continuing support for relationships and friendships; assisting others in meeting and becoming friends with persons with disabilities; and agency support for relationship building. It describes the process used in the Friends project, strategies that seemed to be more and less effective, and it contains many stories and examples.

The manual would be useful for anyone who is interested in supporting a person with disabilities to widen his or her circle of relationships and to develop deeper friendships.

TITLE: Building communities from the inside out: A path toward finding and mobilizing a community's assets

AUTHORS: Kretzmann, J. P., & McKnight, J. L.

PUBLICATION INFORMATION: 1993

Center for Urban Affairs and Policy Research
Neighborhood Innovations Network
Northwestern University
2040 Sheridan Road
Evanston, IL 60208

This guide provides many stories, strategies, and resources related to building stronger communities. This involves looking at the capacities and contributions of all community members, including youth, people with disabilities, and older people, among others.

Chapter 1, "Releasing Individual Capacities," introduces ways to find and use the gifts and talents of local people. Chapter 2, "Releasing the Power of Local Associations and Organizations," describes the efforts of community associations to solve local problems. Chapter 3, "Capturing Local Institutions for Community Building," provides examples of ways in which local institutions (e.g., parks, libraries, schools, colleges) form community partnerships with each other. Chapter 4, "Rebuilding the Community Economy," highlights ways in which communities can capture and build upon existing economic assets. Chapter 5, "Asset-Based Community Development: Mobilizing an Entire Community," summarizes the community-building process presented in this book. Finally, Chapter 6, "Providing Support for Asset-Based Development: Policies and Guidelines," suggests ways in which people and institutions from outside the community can support asset-based community-building activity.

TITLE: Creating responsive communities: Reflections on a process of social change

AUTHOR: Lord, J.

PUBLICATION INFORMATION: 1985

OAMR
1376 Bayview Avenue
Toronto, Ontario M4G 3A3
CANADA

A clear and concise look into one province's struggle in attempting to create a responsive community, this study addresses the idea that, by themselves, more rights and services for people with disabilities and their families are not enough, and that physical presence alone does not mean inclusion. True involvement within the community, it concludes, means necessary supports to allow full participation and opportunities for friendships.

The report focuses not only on lessons related to the emerging vision and strategies this organization used in promoting a sense of community, but also on some of the problems they encountered. A strong family and community emphasis is clear throughout the book, as well as the strength of advocacy in creating such environments. Self-advocacy is mentioned, also, but to a lesser degree. While much of the book deals with the historical development of the province's approach, some interesting and currently relevant principles are set forth in a chapter on assistance to individuals and families.

TITLE: Affectionate bonds: What we can learn by listening to friends

AUTHOR: Lutfiyya, Z. M.

PUBLICATION INFORMATION: 1990

Syracuse, NY: Center on Human Policy, Syracuse University.

In this monograph, Zana Lutfiyya describes a qualitative study conducted with four pairs of friends in the Syracuse area. In each of these pairs, one person has a disability label and one does not. The author offers perspectives on friendship found in the literature, describes each of her informants and their friendships, explores the dimensions and characteristics of friendship, and relates the rights, responsibilities and obligations of friendship in her informants' eyes. She discusses how some friendships move toward greater intimacy while others stay the same or die away, and lays out some of the implications of her study for the human service world, for families, and for people thinking about their own friendships. This ground-breaking study should begin to focus our thinking on what really goes on in friendships, including those between people with and without disabilities.

TITLE: What are we learning about bridge-building?

AUTHORS: Mount, B., Beeman, P., & Ducharme, G.

PUBLICATION INFORMATION: 1988

Communitas, Inc.
73 Indian Drive
Manchester, CT 06040

This monograph opens with the key premise of "bridge-building." "Real integration, the development of genuine networks of support, requires very focused and assertive effort(s) on behalf of facilitators who initiate, support and maintain new

relationships. We call these facilitators "bridge-builders" because they build bridges and guide people into new relationships, new places, and new opportunities in life" (p. 1).

As the sub-title of the monograph suggests, it is a summary of a dialogue between people who are trying to build community for people with disabilities by working as bridge-builders. Most of the monograph presents the reflections of five participants at a day-long discussion on bridge-building in 1988. As this publication appears to be a faithful rendering of people's words, with little attempt at a full written explication of the concepts and terms that form the new language of bridge-building, it may be unsatisfying for someone who is completely new to the idea. However, it does contrast the different perspectives held by proponents of traditional human services with that of bridge-building, and would be of interest to those readers already acquainted with this concept.

TITLE: What are we learning about circles of support?

AUTHORS: Mount, B., Beeman, P., & Ducharme, G.

PUBLICATION INFORMATION: 1988

Communitas, Inc.
73 Indian Drive
Manchester, CT 06040

The authors offer the experiences of several "circles of support" now in existence in Connecticut. Inspired by the efforts of the Joshua Committee over the past decade, the authors helped found circles of support around several people with disabilities. "A circle of support is a group of people who agree to meet on a regular basis to help the person with a disability accomplish certain personal visions or goals" (p. 3). The monograph gives practical information on the process of starting and maintaining a support circle, with several actual examples. Circles of support serves well as both an introduction to the concept and as a useful resource for people already familiar with the issue.

Acknowledging the current fascination with "personal futures planning," the authors provide an important comparison of support circles with person-centered and traditional methods of service planning. And they wisely caution that the process outlined in the monograph is not meant as a model for replication of other support circles. Rather, "the spirit of a circle...is more important than the details of the process, and we hope that the process we describe will help people invite the spirit of support into the lives of other people" (p. 1).

TITLE: Nasty girls, thugs, and humans like us: Social relations between severely disabled and nondisabled students in high school

AUTHOR: Murray-Seegert, C.

PUBLICATION INFORMATION: 1989

Baltimore: Paul H. Brookes Publishing Co.

Based on a qualitative research study, this book is the account of one school's move toward integration, and the peer relations that developed in that school as a result. The author documents the ways in which the school's integration efforts affected student relations and teacher practices. In addition, she relates these findings to the broader themes of quality education, student diversity, and social inequity.

TITLE: Natural supports in school, at work, and in the community for people with severe disabilities

AUTHOR: Nisbet, J. (Ed.)

PUBLICATION INFORMATION: 1992

Baltimore: Paul H. Brookes Publishing Co.

Promoting the position that assistance must be defined by the needs of individuals rather than the requirements of service systems, this volume includes research and first-person accounts related to use of natural supports. Chapters discuss natural supports in relation to: family issues, school, work, residential supports, social support and friendship, among others. Chapters include practice strategies, stories, and reflection on key issues related to developing and sustaining natural support networks.

TITLE: Designing policies in support of inclusive community: Making questions for decision makers

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1989

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

"People in association create neighborhoods, schools, workplaces, marketplaces, and civic organizations. They build inclusive community when their activity calls on, strengthens, and celebrates mutual capacity to welcome, join with, and care for people who have been left out." But, on the other hand as O'Brien tells us, when activities exclude and isolate people, community is diminished. Based on discussion sponsored with the Connecticut Developmental Disabilities Council, O'Brien poses a series of poignant questions to human service and government decision makers. Examples of these questions are: "How can we decrease disincentives to participate in community life?" "How can we insure sufficient cash incomes for people with disabilities?" and "How can we invest in activities that build inclusive communities?"

TITLE: Signs of community building

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1989

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

Based on notes he made while visiting with people involved in community building activities in Phoenixville, PA, in this monograph O'Brien discusses the signs of community building that he saw during his visit: "I was struck by the characteristics that these diverse efforts have in common despite their independent origin and their lack of coordination mechanism." He also suggests that community building touches fundamental everyday concerns, including, "to be healthy and to die well," "to have a safe place in times of confusion," and "to reach out to people in other places."

TITLE: Unlikely alliances: Friendships and people with developmental disabilities

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1993

In A. N. Amado (Ed.), Friendships and community connections between people with and without developmental disabilities (pp. 9-40). Baltimore: Paul H. Brookes Publishing Co.

Friendships are described as "unlikely alliances" for people who are separated and isolated by prejudice against disability. The authors begin by posing a number of questions: What can people with developmental disabilities expect from their social

relationships, particularly their relationships with people without disabilities? Is the meaning of "friend" exhausted by lack of hostility or by benevolent patronage? Or, are some deeper meanings possible, and, if they are, how can people understand them, call them forth, and support them? What challenges come with friendship? The chapter then discusses four dimensions of friendship: attraction, embodiment, power, and community. Through communities of resistance, people can counter the dominant social beliefs that devalue the community's members and their relationships and support one another to get on with their lives.

TITLE: Members of each other: Perspectives on social support for people with severe disabilities

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1992

In J. Nisbet (Ed.), Natural supports in school, at work, and in the community for people with severe disabilities (pp. 17-63). Baltimore: Paul H. Brookes Publishing Co.

This chapter discusses issues related to community membership and belonging for people with severe disabilities. The authors state, "Because people with severe disabilities cannot take membership for granted, those concerned with building stronger, more inclusive communities must consider how people deny membership can be established." They assert that people with disabilities can teach all of us a good deal about the social relationships that are at the foundation of civil life. Some of these teachings can be categorized into three topics: (1) the consequences of long-term exclusion form common memberships; (2) the benefits implicit in recognition as a member, and (3) some of the explicit work necessary to change patterns of exclusion so that a person moves to being known and treated as a member. Examples are provided of each of these topics. The chapter concludes with discussion of the ways in which human services can help, as well as some of the paradoxes of community building.

TITLE: Unfolding capacity: People with disabilities and their allies building better communities together

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1994

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

This paper discusses efforts to build community, based on what the authors have learned by listening to stories of people who have worked together to make important changes in their lives. These changes, all involving people with significant disabilities, include such things as: establishing adequate support for family life; moving from an institution, medical hospital, nursing home, or group residence into one's own home; moving from one's family's home to a home of one's own; getting a job in an ordinary community workplace; and attending school as a member of ordinary classes.

As the authors' see it, "community building happens when people step outside the roles prescribed by the formal and informal administrative structures and the assumptions that typically organize life for people with substantial disabilities" (p. 6). They describe five commitments that contribute to building community: anchor, allies, assistance, agendas, and associations. Each is discussed briefly. The paper concludes by addressing issues related to the importance of community building and tensions in community building.

TITLE: The gift of hospitality: Opening the doors of community life to people with disabilities

AUTHOR: O'Connell, M.

PUBLICATION INFORMATION: 1988

The Community Life Project
Center for Urban Affairs and Policy Research
Northwestern University
2040 Sheridan Road
Evanston, IL 60208

This monograph is part of the growing literature which critiques the human service system even when it is based in the community. It describes the efforts of people with a variety of disabilities to take their place within the community and by others to accept them. O'Connell asserts that community-based services can isolate people with disabilities from community life. Surrounded by paid staff, many clients in the human service system are cut off from the opportunities to meet and develop relationships with typical people.

By sharing the experiences of individuals with disabilities who have been welcomed into the hearts and lives of others, O'Connell introduces a practical definition of hospitality. She suggests that hospitality is "...the fundamental sense that you have to appeal to in asking other people to get involved in this work of welcoming isolated people back into the community." For the author, achieving the fullest possible integration of individuals with disabilities into society involves acts of welcome and hospitality by those who are already members.

This monograph would be useful reading for those interested in the meanings of "community integration" for people with disabilities.

TITLE: Crossing the river: Creating a conceptual revolution in community & disability

AUTHOR: Schwartz, D. B.

PUBLICATION INFORMATION: 1992

Cambridge, MA: Brookline Books

As increasing numbers of people with developmental disabilities have been assisted to live in community-based settings, at the same time, the community services system has failed, in many ways, to help people become participants and members of the community. The conceptual revolution that Schwartz describes involves "rediscovering the importance for all people of being and feeling embedded in a web of personal relationships."

The book begins with two chapters describing efforts to assist people to form community connections (a chapter on connecting people to community associations, by Sharon Gretz; and a chapter on citizen advocacy in Beaver County, Pennsylvania, by A. J. Hildebrand). Following chapters discuss the idea and process of conceptual revolutions, and describe the efforts of the Pennsylvania State Developmental Disabilities Planning Council to foster and support conceptual change. The book concludes with a discussion of issues regarding what keeps people safe, the limitations of community, the role of human services, and the challenges to building community.

TITLE: A story that I heard

AUTHORS: Schwartz, D.B., McKnight, J., & Kendrick, M.

PUBLICATION INFORMATION: 1987

Pennsylvania Developmental Disabilities Planning Council
569 Forum Building
Harrisburg, PA 17120

This monograph is a collection of stories, poetry, and essays about the situation of people with disabilities in American communities. It includes writing by people who have disabilities, family members, and friends and advocates.

TITLE: Social integration and friendship

AUTHORS: Strully, J. L., & Bartholomew-Lorimer, K.

PUBLICATION INFORMATION: 1988

In S. M. Pueschel (Ed.), The young person with Down Syndrome: Transition from adolescence to adulthood. Baltimore: Paul H. Brookes.

In the first part of this chapter, Strully and Bartholomew-Lorimer neatly summarize the experiences of many people with disabilities at the hands of the human service system. By receiving services, individuals are turned into clients and become viewed primarily in terms of their particular disability. They are surrounded by programs and staff, and are cut off from typical people, places and events. One result of this is that people in the community come to believe that segregation is an appropriate response to people with disabilities.

The authors propose that freely-given friendships between typical and disabled people "...are at the root of developing competent, caring communities for us all." They then present two case studies illustrating how to enable a person with disabilities to develop such friendships and the impact of these relationships for the people involved.

TITLE: Ties and connections

AUTHOR: Tyne, A. (Ed.) et al.

PUBLICATION INFORMATION: 1988

King's Fund Centre
126 Albert Street
London, NW1 7NF ENGLAND

This monograph is worth sending to England for. It attempts one of the more comprehensive discussions of interpersonal relationships in the lives of people with developmental disabilities (who are referred to in the publication as having "learning difficulties"). The monograph begins with descriptions of some of the types of relationships that people have and/or desire more of. These include friendships, acquaintances, organizational membership, and being part of a family and a neighborhood. Some basic, common-sense strategies that families, individuals with disabilities, service workers and "typical citizens" might undertake in order to help maintain and increase the existing relationships in a person's life are outlined. The third and last chapter is a cautionary one that explores some of the difficulties faced by people with handicaps in developing a wide range of personal relationships.

5. Women and Caregiving

Today, when the disability field is working toward community integration of people with disabilities, it becomes increasingly important to understand some of the broader social relations that are at work in society and that influence community participation. One of these broader forces is gender relations. Society is fundamentally divided by gender lines and it is not unreasonable to assume that this influences the disability field as well as other aspects of society. Concepts like "community care," "informal care," "family care," and "informal supports" have become increasingly popular within the disability field. Despite this, little attention has been devoted to the concept of "community," and the meaning of "care." Caring is usually defined as women's responsibility and women are often seen as the "natural" caregivers of people with disabilities and other dependent groups. But the fact that the responsibility for caring is still ascribed on the basis of gender has not gained much attention, and women's informal caring work has rarely been the center of focus within the disability field.

This section contains a selected review of the literature on women and community care. This literature is largely British and Scandinavian feminist scholarship that has criticized the policy of community care for assuming and depending on the substantial and consistent input of women's unpaid labor in the home. The literature argues that community care policies are based on an outdated understanding of women's roles in modern societies and suggests that if we do not develop new alternatives that are equally sensitive to women's issues as to disability issues, we may face serious dilemmas that could turn out to be damaging for current attempts to pursue community integration for people with disabilities.

TITLE: Ideologies of caring: Rethinking community and collectivism

AUTHOR: Dalley, G.

PUBLICATION INFORMATION: 1988

Macmillan Education
Houndmills, Basingtoke
Hampshire RG21 2XS
ENGLAND

This book reflects the author's attempt to answer questions about the relationship between feminism, notions of collectivism, and present-day community care policies. She sets out by examining the development of community care policies and what they mean for women and for people who need various support services.

Thereafter follows an analysis of familism which the author links with the wider ideology of possessive individualism. Dalley argues that current thinking about care is based on the principles of familism and possessive individualism and that these could and should be replaced with the principle of collectivism. Society as a whole should take responsibility for its weakest members and the principle of collective responsibility could lead to different and more effective forms of care which are acceptable to the people who need care and allow them to maintain their dignity. The book presents an important step forward in the discussion and understanding of community care. It builds upon previous work, especially the groundwork done by feminist writers who have provided the critique of contemporary approaches to informal care. An interesting and thought-provoking book.

TITLE: A labour of love: Women, work and caring

AUTHORS: Finch, J., & Groves, D. (Eds.)

PUBLICATION INFORMATION 1983

Routledge & Kegan Paul
9 Park Street
Boston, MA 02108

This volume consists of eight chapters which examine various issues in the lives of women who provide unpaid care for children and adults who have handicaps, are chronically ill, or elderly. The chapters are organized in three sections: (1) The Social Context of Caring; (2) The Experience of Caring; and (3) The Economics of Caring. The central focus of the book is on the tension between women's economic independence (actual, potential or desired) and their traditional role as unpaid caregivers. The ten contributors to this volume explore different facets of women's experience of caring, the dilemmas which caring poses for women and the social policy issues raised by the particular topics under discussion. This book was one of the first attempts to give a comprehensive analysis of women's informal caring work. It still remains one of the most important and much cited books on this issue.

TITLE: Women and family care: On the gendered nature of caring

AUTHOR: Traustadottir, R.

PUBLICATION INFORMATION: 1988

Syracuse, NY: Center on Human Policy, Syracuse University.

This paper is based on a qualitative study of families of children with disabilities and the services that provide support to these families. The study challenges the traditional view of families and attempts to explore how stereotypical sex roles influence the caring for a child with a disability within the family. It also examines how traditional ideas and values about the roles of men and women influence the way family support services are provided. The paper provides an analysis of the meaning of care as work (caring for), love (caring about), and as the extended caring role (caring about what happens to people with disabilities in general). The author concludes that the disability field needs to develop a more sensitive perspective on women's issues to further efforts to achieve full community integration of people with disabilities.

TITLE: Policy is personal: Sex, gender and informal care

AUTHOR: Ungerson, C.

PUBLICATION INFORMATION: 1987

Tavistock Publications
(in association with Methuen)
29 West 35th Street
New York, NY 10001

This British book is based on in-depth interviews with nineteen people who provide care for frail and elderly family members. Fifteen of these caregivers are women and four are men. The author describes the lives and experiences of these "carers" (as she calls caregivers) in rich detail and manages to portray her informants in such a way that they come alive on the pages.

The Introduction places the book in the context of other British literature and research on caring and the British social policy of community care (which has many parallels to the U.S. social policy of community integration). The purpose of the book is to fill a gap in the literature on caring and explore, "... the way particular carers in a family constellation emerge, the way that carers talk about and construe the feelings they have about their work, the impact of caring on the relationship between carer and cared for" (page 2).

The findings of this study are fascinating and help develop our understanding of the complicated nature of family care. For example, in an attempt to explain why a particular individual within the family network becomes a carer, Ungerson demonstrates that not all kinship ties are equal. Instead, there is a hierarchy of kinship obligations and carers are "selected," first and foremost according to dominant normative and gendered rules of kinship. In this ranking of kinship obligations, close female kin, especially daughters, are believed to have greater obligation to provide care than sons, and daughters-in-law are expected to serve as primary caregivers when no daughters are available. Another of Ungerson's interesting findings is that there were

significant differences between men and women carers, both in terms of who they cared for, the reasons they gave for providing care, and at what point in their lives they became carers.

Although this book deals with caregivers who are caring for elderly and frail family members, it provides valuable insights that further our understanding of the complicated nature of "family care" for people with disabilities.

TITLE: The meaning and social division of community care

AUTHOR: Walker, A.

PUBLICATION INFORMATION: 1982

In A. Walker (Ed.), Community care: The family, the state and social policy (pp. 13-39). Oxford: Basil Blackwell & Martin Robertson.

This chapter sets out to lay the foundations for a critical assessment of the concept of community care. It examines the meaning of community care from the position of different groups involved; politicians, planners, policy makers, and those in need of care and their families. It also examines the social division of care, particularly between the state and the family. The chapter traces the official development of community care policies in Britain and examines the meaning of community care to the family who provide most of the care. It also discusses some possible future directions for community care policies which attempt to avoid the worst aspects of the current policy, particularly the disproportionate burden it puts on women and families.

TITLE: Women, the "community" and the "family"

AUTHOR: Wilson, E.

PUBLICATION INFORMATION: 1982

In A. Walker (Ed.), Community care: The family, the state and social policy (pp. 40-55). Oxford: Basil Blackwell & Martin Robertson.

This chapter is written from a feminist perspective and argues that the concept of "community" is often used in such a way that it should rather be understood as "family." This is especially true when it is used in connection with the provision of social and welfare services. Moreover, in this same context, the word "family" really means "women." The author criticizes both the concept and ideology of community as it has developed over the past century and suggests that it is riddled with reactionary implications and, in particular, with a vision of the family which is incompatible

with women's liberation. The community, the author argues, is based on an ideology that oppresses women by silently confining them to the private sphere without so much as even mentioning them. The author calls for a new family policy and suggests that the family as it currently exists must change if not only women, but also men and children are to break out of their present situation and harmful behavior patterns based on the current sexual division.

PERSONAL NARRATIVES

Among available narratives by people with disabilities, there are very few based on the lives and words of those who have developmental disabilities. In recent years, there has been more focus on attaining the perspectives of people with developmental disabilities; however, much of this is still compiled and framed by writers who are nondisabled. Within the literature, there is a small but expanding number of accounts written by those with developmental disabilities. This section features these accounts, some as books themselves, and others as shorter narratives with compiled monographs.

TITLE: Know me as I am

AUTHORS: Atkinson, D., & Williams, F.

PUBLICATION INFORMATION: 1990

London: Hodder and Stoughton.

This book is an anthology of poetry, art, and prose by people with learning difficulties. The editors have collected "life stories" from numerous people in such topics as memories, relationships, daily life, a sense of self, struggle and self-determination, oppression, creativity, imagination and fantasy, and transitions. The book concludes with three life stories and an exploration of the key themes of identity, personal struggle, and relationships. The editors also include implications for research and a discussion of their roles as editors.

TITLE: Winnie: "My life in the institution"

AUTHOR: Bolnick, J. P.

PUBLICATION INFORMATION: 1985

St. Martin's/Marek
175 Fifth Avenue
New York, NY 10010

This is the life story of Winnie Sprockett, who was admitted to a state institution for people with mental retardation at the age of six. Winnie's story is written by her friend, journalist Jamie Pastor Bolnick. The story is based on Winnie's autobiography which she wrote to prove to her brother-in-law and the world that she was not retarded

and she desperately wanted her autobiography to be published. Jamie decided to help Winnie tell her story and Winnie's short written account of her life is supplemented by hundreds of hours of interviews the author conducted with Winnie. Winnie's story is told with her own words and gives us a rare insight into the life inside institutions as it is experienced by the people who live there.

TITLE: Annie's coming out

AUTHORS: Crossley, R., & McDonald, A.

PUBLICATION INFORMATION: 1984

Penguin Books Ltd.
Viking Penguin Inc.
40 West 23rd Street
New York, NY 10010

This is the truly remarkable and moving true story of Anne McDonald who, because of severe cerebral palsy, spent fifteen years in an institution, St. Nicholas Hospital for children in Melbourne, Australia, and Rosemary Crossley, who worked as an assistant to the hospital psychiatrist, and the long battle they fought against an obdurate bureaucracy to stop the incarceration of severely handicapped youngsters on grounds of incompetence and infirmity.

Anne describes her struggle to survive against all odds and indignities in an environment that believed her to be "non-human" and incapable of any communication, and her excitement when Rosemary recognized her ability and showed her an alternative, nonverbal means of communication that opened up a new world for her. Staking her job and professional reputation to get Anne and a handful of other young people out of St. Nicholas, Rosemary describes the many hours spent trying to convince unbelieving hospital and court officials that Anne is capable of independent thought, the problems encountered and overcome as Anne makes her first attempt at living outside the institution, and the setbacks and victories that finally led to the closing of St. Nicholas Hospital.

It is a story that will inspire and give renewed hope to advocates, parents and professionals and to those who believe that all people deserve to live with dignity.

TITLE: Emergence - Labeled autistic

AUTHORS: Grandin, T., & Scariano, M. M.

PUBLICATION INFORMATION: 1986

New York: Arena Press.

Temple Grandin is a professional in the field of animal psychology. She is a world leader in research in livestock handling. Grandin is also a woman with autism. In this book she chronicles her life growing up, and now as an adult, with autism. She describes vividly what it was like for her to grow up longing for affection, and yet being so afraid of human contact. She describes to us what it was like to be quick to anger, to be so easily over stimulated, and to be so isolated. Moreover, she helps the reader to come to a better understanding of how those around her affect and form her interactions with the world.

TITLE: Living in the freedom world: Personal stories of living in the community by people who once lived in Oklahoma's institutions

AUTHOR: Compiled by Hayden, M. F.

PUBLICATION INFORMATION: 1997

Minneapolis: Institute on Community Integration, University of Minnesota.

The primary purpose of this booklet is to shore the life experiences of 22 adults with developmental disabilities who once lived in Oklahoma institutions and now live in the community. They were asked questions related to five areas of their lives: home, employment, relationships, community, and dignity and attitudes. Their interviews have been condensed in this publication and, for ease of reading, organized under questions that reflect the themes in their comments. The text, however, remains the actual words of those interviewed.

The monograph also contains some stories from the perspective of family members and staff.

It is through stories such as those told in this booklet that policymakers, service professionals, advocates, families, and others can see the realities of life in institutions and the necessity—as well as the feasibility—of moving people from such segregated settings into the freedom of community life.

TITLE: That time of year: A chronicle of life in a nursing home

AUTHOR: Horner, J.

PUBLICATION INFORMATION: 1982

The University of Massachusetts Press
Box 429
Amherst, MA 01004

This book is a chronicle of Jocey Horner's life in a nursing home. Jocey Horner, a writer and a retired English professor, entered a nursing home in 1974 after becoming disabled by arthritis and a fall where she broke a number of bones. She lived in the nursing home for three years and kept a journal of her experiences. The book provides a very powerful description of these last three years of this one woman's life as well as giving insights into the lives of people who live in nursing homes in general.

TITLE: What happened to you? Writings by disabled women

AUTHOR: Keith, L. (Ed.)

PUBLICATION INFORMATION: 1996

New York: The New Press

Lois Keith compiled collections of fiction, essays, and poetry by disabled women in her new book, What happened to you? Her goal is to give women with disabilities a space to express their views on such topics as abuse, equality, sexuality, prejudice, and legislation dealing with disability issues. These narratives construct disability as a cultural and political issue, not only as a personal one.

TITLE: Mustn't grumble: Writings by disabled women

AUTHOR: Keith, L. (Ed.)

PUBLICATION INFORMATION: 1994

The Women's Press
34 Great Sutton Street
London, EC1 V 0DX
ENGLAND

This edited book, compiled by a disabled woman, presents writings by other women who have a range of physical disabilities. The short stories and poems included in this book range in topic from issues of accessibility to abuse to equality. Disability is framed by these narratives as a social, cultural, and political issue, not only as a personal one. This is an excellent account of disability issues from a woman's perspective. It is powerful, moving, and educating for all readers.

TITLE: The me in the mirror

AUTHOR: Panzarino, C.

PUBLICATION INFORMATION: 1994

Seattle: Seal Press

Written by writer, disability activist, and artist Connie Panzarino, The me in the mirror is an autobiography of the life of this amazing woman. Born with Spinal Muscular Atrophy Type III, a rare disease, Panzarino tells the story of her life as a disabled woman. She describes her life as one of struggles and triumphs, and tells the stories of her relationships with her family, friends, lovers, her turn to lesbianism, and of her years of pioneering work in the disability rights movement. This book is a must read for anyone interested in understanding the experiences of women with physical disabilities.

TITLE: I don't want to be inside me anymore

AUTHOR: Sellin, B.

PUBLICATION INFORMATION: 1995

Translation from German, original work published 1993

New York: Harper Collins Publications, Inc.

I don't want to be inside me anymore, is the story of the life of Birger Sellin, an 18 year old German man who uses facilitated communication (FC). Born in 1973, Sellin eventually at the age of two was labeled as having autism. In 1990 he began to use FC for the first time as a means of communicating with those in his life. Sellin's writings lead the reader into his world and provide considerable insight into the experience, and the pain, of living in our world as a person who has autism. We learn of the struggles and the joys that are felt by Sellin as he learned to communicate through FC. "Now I am going to write a song about the joy of speaking, a song for the mute autistics to sing to institutions and madhouses...."

TITLE: Somebody somewhere: Breaking free from the world of autism

AUTHOR: Williams, D.

PUBLICATION INFORMATION: 1994

New York: Random House, Inc.

The sequel to her autobiography Nobody nowhere: The extraordinary autobiography of an autistic, Somebody somewhere continues the life story of Australian born writer and teacher, Donna Williams. Specifically, in this book Williams tells the story of her life in the four years since having been diagnosed with autism. She accounts what it was like for her to move away from her isolating world of autism and to overcome the prejudice of her teachers and fellow students. We also learn of her experiences with reaching out to others for friendship and in shedding light on her experiences of living in a world in which autism is so deeply misunderstood. For educators and those immersed in learning to become educators, Williams also provides the reader with her thoughts on education and insight into students labelled with autism.

WOMEN WITH DISABILITIES

Anyone looking for materials about the lives and experiences of women with disabilities a few years back would have found little to read. Today there is a growing body of literature addressing different aspects of the lives of women and girls with disabilities. At the same time, only a small proportion of this is inclusive of women with developmental disabilities. These writings do not fall into one field of study; instead, they come from a wide range of disciplines and are often interdisciplinary in nature. As a result these materials are scattered across many fields of study which makes it hard to gain an overview of what already exists and even harder to know where to look for materials. Because of how hard it is to find writings about women with disabilities one frequently hears statements like, "There is nothing written about women with disabilities." Although much remains to be learned about women and girls with disabilities, this selected bibliography shows that there already exists a substantial body of literature on the topic.

This section is not a comprehensive listing of the literature on women with disabilities. Instead we have selected writings that reflect the diversity found within this literature. We hope this section will serve as a useful starting point for people who are looking for materials on women with disabilities.

TITLE: The new our bodies, ourselves: A book by and for women

AUTHOR: The Boston's Women's Health Book Collective

PUBLICATION INFORMATION: 1984

Simon & Schuster
Simon & Schuster Building
Rockefeller Center
1230 Avenue of the Americas
New York, NY 10020

When Our bodies, ourselves was first published in 1969 there was practically no information easily available about women's health issues. The first publication of this book encouraged many women to explore the health issues most important to them. This new edition of Our bodies, ourselves has been considerably expanded from previous editions of the book. One of the additions is the inclusion of women who have disabilities and a disability perspective is presented in most chapters. Our bodies, ourselves has finally become a book on women's health issues for all women. Hopefully this book will serve as a model as to how other generic books on women's

health, education, sexual abuse, and so on, can include disability issues as an integral part of the topic. Although the authors should be praised for including women with disabilities it should also be mentioned that some issues of importance to women with disabilities get much less attention than needed. Examples of this are the problems some disabilities can cause during pregnancy and childbirth.

TITLE: With the power of each breath: A disabled women's anthology

AUTHORS: Browne, S. E., Connors, D., & Stern, N. (Eds.)

PUBLICATION INFORMATION: 1985

Cleis Press, A Women's Publishing Company
P.O. Box 8933
Pittsburgh, PA 15221

The quality of writing of this collection of essays, poetry, interviews, and first-person account is uneven and the editors' articulate and informative introductions sometimes outshine the collected pieces. All the women who contributed to the book have a disability. Most of the book consists of first person accounts of being a female and having a disability, but a few conceptual pieces are also included. The stated purpose of the book is to "bridge the gap that separates women with disabilities from one another and from the non-disabled world" (p. 10) and the book reflects these women's resistance against the silencing of women with disabilities.

The editors set out with a strong political commitment to produce an anthology representative of all women with disabilities. Although that proved to be impossible, the book addresses a broad spectrum of disability issues and the contributors cross the lines of race, age, class, sexual orientation, geographical location and type of disabilities. The book also includes interviews with women who are labeled mentally retarded, a group which often has been excluded in the literature on women with disabilities. This book is born out of a group of women with disabilities who also are feminists and reflects their experiences of discrimination because of their disabilities in addition to the traditional sexism. The majority of the pieces in this book are angry and speak out with bitterness regarding the isolation, despair and powerlessness women with disabilities face in their lives. Some of the pieces are both inspiring and very moving.

TITLE: Women and disability: The double handicap

AUTHORS: Deegan, M. J., & Brooks, N. A. (Eds.)

PUBLICATION INFORMATION: 1985

Transaction Books
Rutgers University
New Brunswick, NJ 08903

This book is the first major collection of scholarly writing about women who have disabilities and contains 11 chapters dealing with various aspects of the lives of women with disabilities. The major factors that unify this collection are a central focus on the double minority status of women with disabilities, the lack of information available about their lives and experiences, and the need to change the conditions that perpetuate the structural inequality women with disabilities experience.

Two of the chapters, Chapter 2, by Fine and Asch, "Disabled Women: Sexism without the Pedestal," and Chapter 4, by Deegan, "Multiple Minority Groups: A Case Study of Physically Disabled Women," provide a conceptualization of women with disabilities that has had a significant impact on other people's thinking and writing about women with disabilities. In her chapter, Deegan points out the multiple discrimination against women with disabilities; as a woman and as a person with a disability. Deegan's discussion of the effects of the multiple minority status of women with disabilities is useful in examining structural discrimination in employment, education and other areas. Fine and Asch's conceptualization of disabled women as "roleless" has already gained much note in subsequent literature. The remaining sections focus on specific types of disabilities and their consequences for women or specific problem areas, such as mothering and self-help. Other issues covered are the economic effects of a multiple minority status and the negative consequences of present policies on the lives of women with disabilities.

The book is a beginning step in unraveling the interaction between more than one minority status being held concomitantly by an individual and a group. While the quality of the articles is not uniform, they all provide insights into the problems and experiences of these women and add immeasurably to the conceptual and theoretical understanding of the lives of women with physical disabilities. One shortcoming of the book is that it only deals with women who have physical disabilities. Another is that rather than examining class and race issues, it is dominated by white middle class views and values.

TITLE: Ourselves growing older

AUTHORS: Doress, P. B., & Siegal, D. L.

PUBLICATION INFORMATION: 1987

(In conjunction with the Midlife and Older Women's Book Project and The Boston's Women's Health Book Collective.)

Simon and Schuster
Simon & Schuster Building
Rockefeller Center
1230 Avenue of the Americas
New York, NY 10020

Like its predecessor, Our bodies, ourselves, this book builds upon the tradition of self-help and focuses on prevention and changes to create healthier life-styles. It is aimed at promoting self-acceptance of older and middle aged women by themselves and stresses the empowerment of midlife and older women in confronting the challenges of growing older. This is an informative book which covers a wide range of topics, including a variety of physical and mental ailments common to middle age and older women. Included throughout the text are practical tips for dealing with specific physical and mental problems. A resource guide in the back of the book lists articles of interest, a guide to community services and support groups. A good resource book.

TITLE: Across borders: Women with disabilities working together

AUTHORS: Driedger, D., Feika, I., & Batres, E. G. (Eds.)

PUBLICATION INFORMATION: 1996

Gynergy Books
P.O. Box 2023
Charlottetown, PEI C1A 7N7
CANADA

This edited book with an international perspective highlights the experiences of women with disabilities working together. Each chapter is written by disabled women leaders. The chapters explore how women with primarily physical disabilities join together to demand participation in society and document their experiences of working together and of forming disabled women's self help groups. Across Borders begins with a description of the growth of the disability movement worldwide and discusses the issues facing women with disabilities in the areas of employment, education, attitudes, and violence. The essays are grouped by region, and also include poetry and photographs.

TITLE: Imprinting our image: An international anthology by women with disabilities

AUTHORS: Driedger, D., & Gary, S. (Eds.)

PUBLICATION INFORMATION: 1992

Gynergy Books
P.O. Box 2023
Charlottetown, PEI C1A 7N7
CANADA

The editors compiled articles by women with disabilities from 17 countries. They stress the importance of understanding disability not as an inherent tragedy but as a social problem created by a lack or sensitivity and awareness to the experiences of women with disabilities and to the physical, social, and psychological barriers that occur as a result of this insensitivity. The book is organized around its central principle that women with disabilities are citizens with the means to contribute to their societies. It is divided into five sections. They include: Our Image in the Family, Our Image in the Community, Imprinting Our Image on the World, In Spite of the World, and Dealing with the World.

TITLE: Women with disabilities: Essays in psychology, culture and politics

AUTHORS: Fine, M., & Asch, A. (Eds.)

PUBLICATION INFORMATION: 1988

Temple University Press
Philadelphia, PA 19122

This is the a comprehensive edited collection of scholarly writing about women with disabilities. Fine and Asch, the editors of this volume, have, for a number of years, been involved in examining what it means to be a woman with a disability in today's society. Their early conceptualization of the problems facing women with disabilities has influenced and informed other people's thinking. Now these two women have collected the work of 22 writers and thinkers to explore the psychological, cultural and political dilemmas currently faced by approximately 18 or 19 million women with disabilities in America. The volume covers a wide range of issues, reviews the most recent thinking on this subject and raises provocative new areas for future exploration.

The 13 essays in the volume are loosely organized in three categories; "Bodies and Images," "Disabled Women in Relationships," and "Policy and Politics." In addition there is a lengthy introduction by Asch and Fine where they review past work (and neglect) on this subject and point toward future exploration. The editors also close the book with an "Epilogue: Research and Politics to Come." Like all collections of essays, the quality is uneven. At the same time this is an important document about the lives of girls and women with disabilities in American society today. It is also notable that the editors have made attempts to cover broader issues than previous collections on women with disabilities. First, this volume covers a broader range of disabilities than many previous writings. An example of this the inclusion of women with developmental disabilities, a group that has traditionally been neglected in volumes on women with disabilities. Second, the volume deals with issues that often have been neglected such as disability and ethnicity; the moral dilemma between reproductive rights and disability rights; and an analysis of the exclusion of women with disabilities from the women's movement. The volume also includes a discussion about girls with disabilities. This is a book that everyone interested in the lives and experiences of women with disabilities should read.

TITLE: Feminism and disability

AUTHOR: Hillyer, B.

PUBLICATION INFORMATION: 1993

University of Oklahoma Press
1005 Asp Avenue
Norman, OK 73019-0445

Written out of a need in the feminist movement to include women with disabilities and a need in the disability rights movement to address the unique experiences of women, Feminism and disability combines the personal, political, and intellectual aspects of feminist theory and disability theory. Hillyer discusses such issues as body awareness, community, nature and technology, and the ways in which cultural standards of language, independence, and even mother-blaming are constructed. She also challenges political movements which stress productivity and normalization in order to include more types of people and more aspects of the human condition.

TITLE: Feminist perspectives of family care: Policies for gender justice

AUTHORS: Hooyman, N. R., & Gonyea, J.

PUBLICATION INFORMATION: 1995

Sage Publications
P.O. Box 5084
Newbury Park, CA 91359

Hooyman and Gonyea critically examine the act of caregiving through a feminist perspective. Given that over 75% of care provided to family members is provided by women, the authors analyze the impact of this caring on women's economical, social, and personal experiences. Furthermore, they examine how changing economic structures, changing families, and the changing workforce have affected the lives of women who provide care. The authors argue for structural changes in the economy, social institutions, and attitudes in order to improve the lives of women. Hooyman and Gonyea also explore the implications for social policy if caregiving is defined as a women's role and how current social policies are oppressive to women. Their recommendations for change include workplace supports, health care and long term care policies, and economic and social supports for caregivers.

TITLE: Women and disability

AUTHOR: Lonsdale, S.

PUBLICATION INFORMATION: 1990

St. Martin's Press
175 Fifth Avenue
New York, NY 10010

Lonsdale explores how women with physical disabilities experience the double discrimination of being both a woman and a disabled person in society. Placing physical disability in a social and political context rather than an individual one, she uncovers how women with disabilities have been rendered invisible, how they see their self image and body image, how physical disability often leads to dependence, and how women experience a loss of civil liberties and how they face discrimination. Lonsdale also considers the ways in which these situations can change for women, specifically, how policy practices can change so that women can achieve greater

independence. Chapters include subjects such as the social context of disability, invisible women, self image and sexuality, employment, financial consequences of disability, discrimination, and independence.

TITLE: Voices from the shadow: Women with disabilities speak out

AUTHOR: Matthews, G. F.

PUBLICATION INFORMATION: 1983

The Women's Educational Press
16 Baldwin Street
Toronto, ON
CANADA

This book explores the lives of women with disabilities in Canada and is based on interviews with 45 women with disabilities. The author herself has a physical disability and the book is a mixture of her own autobiography and the interviews. The result is a very readable and interesting account of the lives of women with disabilities, some of whom live in institutions and others who live in the community.

The book is candid in its critique of the medical and rehabilitation professionals, institutions and the attitudinal and physical barriers in society. It explores the feelings of women with disabilities about themselves and their relationships with others. It points out that many doctors and social workers as well as society in general think that women with disabilities are asexual and therefore not in need of information on birth control or what is possible in the way of having children or a sex life. Other issues addressed are employment, education, housing, parenting, accessibility and social and governmental assistance.

The introduction to the book is written by Pat Israel and Cathy McPherson, "two feminists with disabilities" (as they call themselves). They discuss, among other things, the relations between the disability rights movement and the women's movement and criticize how un-accessible the women's movement has been for women with disabilities.

TITLE: Feminist research and "community care"

AUTHOR: Morris, J.

PUBLICATION INFORMATION: 1991

In J. Morris, Pride against prejudice: Transforming attitudes to disability (pp. 146-168). Pittsburgh: New Society Publishers.

New Society Publishers
4527 Springfield Avenue
Philadelphia, PA 19143

In this chapter, Morris argues that while feminists have paid much attention to "community care" policies, they have virtually ignored the experiences of disabled women. She asserts that feminist concerns about women's roles as caregivers must be re-examined from a disability perspective. Traditionally, feminists have rejected community care policies which depend on women's unpaid labor in the home, thereby excluding women from the labor market and reinforcing their economic dependence on men. While these feminists would call for community care in residential settings, Morris argues that disabled people want services within the community, and therefore reject the traditional feminist view of community care.

The author claims that the differences between these two views is because the feminists who are writing and researching in the area of women and care do not actually need physical care themselves. In ignoring the experiences of those women who need care, they silence disabled women and force them into the role of the other. These feminists only see women as carers, not as those being cared for, thereby legitimizing one side and marginalizing the other.

In response to these feminists, Morris offers a critique from a disabled feminist perspective. She argues that research needs to examine the meaning of "caring for" and "caring about" and especially the meaning of home (separated from the political feminist critique of the family). She asserts the feminist scholarship needs to understand this issue from a disability perspective and to see as the goal disabled women living in the community and receiving supports from caregivers whose work is valued, appreciated, and adequately compensated.

TITLE: Independent lives: Community care and disabled people

AUTHOR: Morris, J.

PUBLICATION INFORMATION: 1993

Macmillan Press
Hound Mills
Basingstoke
Hampshire RG21 2XS
ENGLAND

This book is a qualitative study which explores the experiences of disabled people who receive help with daily living activities. Based on in-depth interviews with 50 people and using a feminist perspective and a disability rights perspective, Morris challenges the discourse around community care policies. She illustrates how

residential care is often replaced by institutionalization in community settings, and further challenges policy makers and those who provide care to recognize the basic civil rights of people with disabilities, and that part of their civil rights is to receive physical help.

TITLE: Pride against prejudice: Transforming attitudes to disability

AUTHOR: Morris, J.

PUBLICATION INFORMATION: 1991

New Society Publishers
4527 Springfield Avenue
Philadelphia, PA 19143

Morris, a disabled feminist and activist, provides a feminist analysis to the study of the experiences of women with disabilities. Basing her arguments on the feminist principle that the personal is political, Morris eloquently challenges such issues as prejudice, abortion, and the notion that people with disabilities lead lives that are not worth living. She further discusses the history of people with disabilities in institutions and under the Nazi regime. Morris also examines the meaning of disability in Western culture and the meanings of a history of segregation, dependence, and an emerging independence of people with disabilities. Pride against prejudice is a commentary on political activism and rights, and stresses the need to fight back against the prejudice, stereotypes, and oppression of an ableist culture.

TITLE: The politics of caregiving

AUTHOR: Munford, R.

PUBLICATION INFORMATION: 1994

In M. H. Rioux & M. Back (Eds.), Disability is not measles: New research paradigms in disability (pp. 265-284). North York, ON: Roeher Institute.

The Roeher Institute
Kinsmen Building, York University
4700 Keele Street
North York, Ontario M3J 1P3
CANADA

This chapter explores the meaning of care to those who give and receive it in order to challenge the current way it is organized. It examines the ways in which the caregiving relationship can be changed and how alliances with people with intellectual disabilities can be formed. The author bases her argument on the premise that non-disabled researchers and writers need to situate themselves in the research project and in the particular situation they are writing about.

Munford's chapter is divided into three sections. The first section provides a context by discussing important influences on the researcher and writing process. She argues that researchers must understand how their research can reinforce the powerlessness of those they are researching. She feels that researchers need to form equitable relationships with the people with disabilities whom they are researching. The second section focuses on important concepts which are necessary to understand what happens in a caregiving relationship. The third section explores the role of social policy in constructing the lives of people with disabilities. The author argues for the importance of examining social policy in terms of disability of a social and political category. Hopefully then social policies will have possibilities for choice and empowerment for people with disabilities.

TITLE: Bridging the gap: A national directory of services for women and girls with disabilities

AUTHOR: National Clearinghouse on Women and Girls with Disabilities

PUBLICATION INFORMATION: 1990

Educational Equity Concepts
114 East 32nd Street
New York, NY 10016

The National Clearinghouse on Women and Girls with Disabilities has compiled a national directory of services and support groups for women and girls with disabilities. This document contains more than three hundred listings of organizations that provide services to meet the needs of women and/or girls with disabilities. Each entry includes organization name, address, telephone number, contact person, region served, date established, whether they respond to inquiries by phone or by mail, if they have a newsletter, and a brief description of their programs and services. The services included in this directory cover a wide range of areas of importance for women with disabilities such as educational services and offices of disability services at universities; support groups and other self-help groups for women with disabilities; government and non-government organizations focusing on or including women with disabilities; generic services which also provide services for women with disabilities such as rape crises and planned parenthood; and more. This is a unique directory that will be of extreme importance for women with disabilities in terms of breaking the isolation they

so often experience and helping them find appropriate services and supports. As the first national directory of services and support groups for women with disabilities, it will undoubtedly serve to help women with disabilities find each other and build connections.

TITLE: The tentative pregnancy: Prenatal diagnoses and the future of motherhood

AUTHOR: Rothman, B. K.

PUBLICATION INFORMATION: 1986

Viking Penguin
40 West 23rd Street
New York, NY 10010

The technology that makes prenatal screening and diagnosis possible is usually celebrated by the medical establishment as a triumph for modern medicine as a means to prevent disability. This technology is also seen as a way to improve the lives of families and societies. This book deals with this new technology but goes beyond the technology itself and looks at how it affects the lives of women who use it. This is a study of 120 women who have used amniocentesis, the most used form of prenatal testing. All the women in this study who received "bad diagnoses" (that is the fetus was diagnosed as having some form of a disability) made the decision to have an abortion. Rothman describes with great sympathy the pressure on women to use the technology and to undergo abortion if the fetus is "defective." Rothman sees these women as victims of technology, sacrificing themselves to spare their children from suffering.

The subject of this book is at the center of one of the dilemmas faced by feminists with disabilities, that is, feminists with disabilities who have participated in the fight for women's rights to control their own bodies, who are now faced with the fact that this right is used to selectively abort "defective" fetuses.

TITLE: Women with disabilities: A survey of health-related experiences

AUTHORS: Savage, A., & Georgeson, S.

PUBLICATION INFORMATION: 1989

The Disabled Persons Assembly (NZ), Inc.
P.O. Box 143, 629 Main Street
Palmerston North, NEW ZEALAND

This book from New Zealand documents health experiences of women with disabilities. It is based on interviews with 60 women from three disability categories: 34 of the women had physical disabilities, 12 had intellectual disabilities, and 12 had psychiatric disabilities. The authors conclude by summarizing some of the findings of the study, and state that the experiences of these women show some fundamental issues about health and the health services they receive. Among the things they list are (1) lack of information regarding women with disabilities about the nature of their disability, as well as the implications of these disabilities; (3) the unequal relationships between health professionals and women with disabilities; (4) women with disabilities are not listened to and are excluded from decision making about their own health; (5) lack of information about side effects of medications; (6) disability is negatively viewed by health professionals and the general public alike; (7) women with disabilities fear being integrated into a community that does not have the resources to support them; and (8) women with disabilities view the availability of both personal and community support as vital.

The last section of the book provides recommendations for change based on the findings of the study.

TITLE: Disabled, female and proud! Ten stories of women with disabilities

AUTHOR: Rousso, H. (Ed.)

PUBLICATION INFORMATION: 1988

Exceptional Parent Press
605 Commonwealth Avenue
Boston, MA 02215

This book is edited by Harilyn Rousso, a woman with a disability, with photographs by Flo Fox, a visually-impaired photographer, and written by ten contemporary women with disabilities. These ten women offer their experiences and ideas about work, relationships, pregnancy, motherhood, life-styles, and how they got to where they are now. Each woman discusses the prejudice, barriers and difficulties she faced and offers advice to the reader about how to overcome these. The jobs these women hold span a variety of fields: some of them work in the creative arts; others in mathematics and science; some work in business; and others in human services. The ten women have various disabilities, and are of diverse age, race, class and language backgrounds.

The book grew out of the work of Harilyn Rousso, a social worker and therapist, who created a big-sister project for women and girls with disabilities in New York City to address the lack of role models in the media and the community for young women with disabilities. The book is intended to serve as a much needed resource to

counteract the isolation so many women with disabilities experience in their struggles with work and life. It is also intended to provide positive role models for women and girls with disabilities.

TITLE: With wings: An anthology of literature by and about women with disabilities

AUTHORS: Saxton, M., & Howe, F. (Eds.)

PUBLICATION INFORMATION: 1987

The Feminist Press
City University of New York
311 East 94th Street
New York, NY 10128

This is a collection of literary writings by and about women with disabilities. This anthology of essays, stories, and poetry conveys the experiences and feelings of women with disabilities. Among the 30 contributors to this book are such well-known names as Alice Walker, Adrienne Rich, Muriel Rukeyser, Vassar Miller, Nancy Mairs, Laurel Lee and Mary Wilkins Freeman. A powerful and moving book about the strengths, the struggle, the dignity, the intelligence, the humanity, and the courage of women with disabilities.

TITLE: A mother's work is never done: Constructing a "normal" family life

AUTHOR: Traustadottir, R.

PUBLICATION INFORMATION: 1995

In S. J. Taylor, R., Bogdan, & Z. M. Lutfiyya (Eds.), The variety of community experience (pp. 47-65). Baltimore: Paul H. Brookes Publishing Co.

The author examines the everyday lives of families of children with disabilities. She explores the ways in which the family attempts to construct an "ordinary" or "normal" family life. Traustadottir analyzes the gendered organization involved in constructing and maintaining a normal family life. Through qualitative research based on interviews and participant observation, Traustadottir found that families of children with disabilities devote much time trying to lead a "normal" family life. For the most

part this meant following the traditional family pattern of full time wife and mother and working father. She suggests that presence of disability in the family causes parents to compensate by conforming as closely as possible to traditional gender roles.

The author also discusses implications for professionals, stating that they need to be aware of individual perspectives of families. She also addresses how broader socio-cultural issues such as class, race, ethnicity, and gender influence the lives of families of children with disabilities.

TITLE: Disability reform and the role of women: Community inclusion and caring work

AUTHOR: Traustadottir, R.

PUBLICATION INFORMATION: 1992

Unpublished Doctoral Dissertation
Syracuse University
Syracuse, NY 13244

This dissertation is a feminist qualitative study of the role of women in the community inclusion of people with developmental disabilities. The author demonstrates that despite the fact that women constitute the vast majority of those who do the day-to-day work of inclusion, their contributions go unnoticed and are invisible. Through in-depth interviews and participant observation, the author examines women's caregiving and relationship building in the areas of family as mothers of children with disabilities, in the human service system as paid workers, and in the context of friendships. Crucial to this study is the idea that caring is not a personality trait inherent in being a woman, rather it is created through social interactions. Women are recruited for caregiving through powerful social arrangements and this social construction of women as caregivers continues throughout their lives.

The analysis outlines the multiple ways women's work is made invisible, and that the field of disability studies does nothing to make this work visible. In fact, it often exploits women by not recognizing and understanding the work that they do. The author concludes by articulating areas for change in the fields of feminist scholarship and disability policy.

TITLE: The meaning of care in the lives of mothers of children with disabilities

AUTHOR: Traustadottir, R.

PUBLICATION INFORMATION: 1991

In S. J. Taylor, R. Bogdan, & J. A. Racino (Eds.), Life in the community: Case studies of organizations supporting people with disabilities (pp. 185-194). Baltimore: Paul H. Brookes Publishing Co.

In this qualitative chapter, Traustadottir explores the gender difference in caring for a child with a disability within the family. She discovered that the responsibility for caring is based on gender. The study revealed the term "caring" as a complex phenomenon that has at least three meanings. Caring for, the work, means acquiring specialized knowledge and techniques which are associated with professional work (not traditional mother work). The second definition is caring about, the love. This refers to relationships and emotions. The third definition is the extended caring role. The meaning of care extends from a woman's own child to broader community or societal concerns surrounding people with disabilities and the way they are treated in society.

The author also discusses gender roles and the responsibility of caring. The woman is usually responsible. This begins when she decides to keep her child at home rather than a residential setting. This is almost always the mother's decision because it is understood that she will be the primary caregiver. In addition to this work, she is responsible for the housework and other family work. Furthermore, the baby is not seen as a restriction on family life if only the mother is restricted. However, if the family feels restricted then the situation is considered problematic. Some women see the job of caring as their "natural" responsibility, while others resist this traditional gender role.

The author concludes by stating that disability studies needs to look at gender as a critical issue and needs to take notice and look critically at issues of gender and the roles of mothers and fathers in families.

TITLE: Women with disabilities: Issues, resources, connections, revised

AUTHOR: Traustadottir, R. (updated by Harris, P. J.)

PUBLICATION INFORMATION: 1997

Syracuse, NY: Center on Human Policy, Syracuse University.

The materials that have been compiled into this information package on women with disabilities are intended to serve as an introduction for those who are interested in learning about the lives of women and girls with disabilities and the specific issues they face in today's society. In addition to introducing the lives and experiences of women with disabilities, the primary purpose of this package is to provide an overview of the existing materials in an attempt to make them more accessible to those who are interested in this topic.

The package is divided into five parts. Part I contains an article which provides an overview of the literature and some of the major issues facing women with disabilities in today's society. Part II is an annotated listing of resources written by and/or about women and girls with disabilities. Part III contains information about teaching materials about women and girls with disabilities. This part also lists other practical materials, such as a manual for accessibility. Part IV provides information about where to find services and support groups for women and girls with disabilities and how to start networking projects. This part also contains information about women's periodicals and organizations which include women with disabilities. Finally, Part V lists World Wide Web sites about and by women with disabilities.

TITLE: Research by/for/with women with disabilities

AUTHOR: Wight-Felske, A.

PUBLICATION INFORMATION: 1990

The G. Allan Roeher Institute
Kinsmen Building
York University
North York, ON M3J 1P3
CANADA

The Roeher Institute is a Canadian-based information and advocacy organization for people with cognitive disabilities. They address a wide range of issues, including community living, jobs, and support, and provide information about issues concerning disability rights. This specific publication has been written to raise the awareness of researchers to the issue of disability and to give a voice to women with disabilities. Specifically, it outlines the ways in which women with disabilities have been excluded from research, provides a framework for research for and with women with disabilities, presents a guideline for non-stereotyping language, and also address the ways in which people can be informed about women and disabilities.

TITLE: Building community: A manual exploring issues of women and disability

AUTHOR: Women and Disability Awareness Project

PUBLICATION INFORMATION: 1989

Educational Equity Concepts
114 East 32nd Street
New York, NY 10016

This manual examines the connection between discrimination based on gender and discrimination based on disability, and addresses disability as a political issue; civil rights issue; as a human relations issue; and as a personal experience. It is intended to build community between diverse groups. The authors point out that the lack of opportunities within schools and organizations to learn about what it means to be a person with a disability results in widespread ignorance about people with disabilities. The authors intend the manual partly for use in schools as a general introduction to the topic, for teachers as well as students, and partly to be used within women's organizations to raise general awareness about issues faced by women with disabilities and strategies to meet the needs of women with disabilities within the organizations. In disability rights organizations the manual could serve to raise awareness about the particular needs of women with disabilities and how their lives and experiences differ from those of men with disabilities. In both women's and disability organizations the manual can be used to train staff as well as to inform the general membership about the connection between discrimination based on gender and disability.

The manual contains background information on disability rights issues and about women and girls with disabilities, an annotated bibliography and selected readings about women with disabilities. Lastly, the manual contains very practical guidelines and materials to conduct workshops on women with disabilities, including workshop formats that will allow activists, educators, and other trainers to explore disability issues in a wide variety of settings. This is a very practical and informing manual for anyone interested in the connection between gender and disability.

This manual was first published in 1984. The 1989 edition has been expanded to include the specific needs of young women with disabilities.

SEXUALITY

The sexuality of people with disabilities is an area that has received a considerable amount of attention and much of the writing in this area reflects the struggle of people with disabilities to be seen as sexual beings.

TITLE: Responding to the sexuality of people with mental handicap

AUTHORS: Coley, L., & Marler, R.

PUBLICATION INFORMATION: 1987

In G. Horobin (Ed.), Sex, gender and care work (pp. 66-81). New York: St. Martin's Press.

St. Martin's Press
175 Fifth Avenue
New York, NY 10010

This chapter states that the sexuality of people with mental handicap has been largely ignored and in the few instances where it has been considered, the response has been restrictive and over-protective. (The book is British and uses the word mental handicap for mental retardation.) The authors trace some of the restrictive attitudes to the way human services are operated. For example, many group homes are run by Christian groups who insist that residents live up to what is seen as "Christian principles of high morals and values."

The authors state clearly that people with mental retardation have the same rights and needs to enjoy their sexuality as anyone else, and should have the same right to marry or cohabit as anyone else.

Although the chapter does not direct much attention to issues of specific concern to women with disabilities it raises issues of great concern to them, such as forced sterilization and forced abortion.

TITLE: Sexuality and people with intellectual disability

AUTHORS: Fegan, L., Rauch, A., & McCarthy, W.

PUBLICATION INFORMATION: 1993

Baltimore: Paul H. Brookes Publishing Co.

"Many people with intellectual disability are disadvantaged with regard to sexual fulfillment and enjoyment. They need to be helped to better understand their sexuality and to incorporate this dimension of themselves into their lives as a whole." Based on the underlying premise that all people, regardless of intellectual ability, are sexual beings. Fegan, Rauch, and McCarthy help readers, be they a parent of child with a disability, caregivers, or disability workers, to see that people with intellectual disabilities are sexual beings and have sexual needs. The authors provide many useful suggestions to approaching the issue of sexuality with people with an intellectual disability. Issues discussed include: physical development, masturbation, sexual intercourse, homosexuality, sexual health, fertility, and safe sex.

TITLE: Reproductive issues for persons with physical disabilities

AUTHORS: Haseltine, F. P., Cole, S. S., & Gray, D. B. (Eds.)

PUBLICATION INFORMATION: 1993

Baltimore: Paul H. Brookes Publishing Co.

This book challenges the social stereotypes about reproduction and disabilities and presents the fact that people with disabilities do have sexual needs and desires. The chapters in this book explore the reproductive issues associated with congenital and acquired disabilities, and include such topics as fertility, health care needs, contraception, adoption, genetic counseling, pregnancy, parenting, sexually transmitted diseases, sexual dysfunction, and reproductive physiology. Contributing authors include researchers, people with disabilities, academics, medical professionals, and psychologists.

The book is an interesting blend of academic articles and personal stories. For examples, a rather clinical article about how a woman with a disability may experience pregnancy, labor and delivery, is preceded by a personal account of a woman with a physical disability sharing her experiences of pregnancy and childbirth. By weaving these two styles together in this way, the book becomes more than a clinical guide to reproduction and sexuality, rather it becomes a book for people with disabilities to share their experiences in these areas, which is a much needed addition to the literature on sexuality and disability.

TITLE: I contact - Sexuality and people with developmental disabilities (2nd Ed.)

AUTHOR: Hingsburger D.

PUBLICATION INFORMATION: 1991

VIDA Publishing
P.O. Box 597
Mountville, PA 17554

In 1990, Hingsburger first wrote this book for service providers with the underlying premise that "all people can love and all people can make human contact." Starting with the story of his own `hang-ups' in counseling people with developmental disabilities in relation to their sexuality and expression of this sexuality, Hingsburger teaches the reader a valuable lesson about who knows best what an individual needs. Other issues Hingsburger teaches us about include: the basis of love, privacy, relationships, and sexuality counseling.

TITLE: Affection, love, intimacy, and sexual relationships

AUTHORS: Jurkowski, E., & Amado, A. N.

PUBLICATION INFORMATION: 1993

In A.N. Amado (Ed.), Friendships and community connections between people with and without developmental disabilities (pp. 129-151). Baltimore: Paul H. Brookes Publishing Co.

As friendship for persons with developmental disabilities receives greater attention and support, attention also needs to be paid to the importance of relationships that include love and physical affection. In this chapter, key issues regarding the sexuality of individuals with disabilities are explored, including how persons with disabilities themselves view the topic. Some sexual "subcultures" for individuals with disabilities that have been created as a result of the service system are described, as well as system factors that affect normal sexual development. The importance of sexuality education is delineated from the vantage point of enhancing quality of life and enhancing relationships, and as an important precursor to prevention of abuse.

TITLE: Understanding and expressing sexuality: Responsible choices for individuals with developmental disabilities

AUTHOR: Monat-Haller, R. K.

PUBLICATION INFORMATION: 1992

Baltimore: Paul H. Brookes Publishing Co.

"For too long individuals with developmental disabilities and mental retardation have been expected to be asexual." Consequently, these people have been expected to repress their inherent sexuality and to obey rules and regulations that deny their right to sexual expression. Here, the author, through the use of case studies, discusses topics and issues including: human anatomy and physiology, maturation and body changes, inappropriate sexual behavior, abuse, and offenders, birth control options, sexually transmitted diseases, aspects of psychosocial-sexual behavior and psychosocial development, and marriage and parenthood.

ABUSE AND VIOLENCE

Abuse and violence toward people with disabilities is another area that has received increasing attention. For example, much of this literature is based on studies that show that women with disabilities are at a much greater risk of being sexually abused than other women. This is true in society in general, and within residential facilities in particular. The literature listed below reflects these studies, as well as writings that have attempted to explain the increased vulnerability of people with disabilities to sexual abuse, and suggestions about what preventive measures can be taken.

TITLE: Just say know: Understanding and reducing the risk of sexual victimization of people with developmental disabilities

AUTHOR: Hingsburger, D.

PUBLICATION INFORMATION: 1995

Diverse City Press
BM 272, 33, rue des Floralies
Eastman, PQ J0E 1P0
CANADA

This book is full of stories and strategies for confronting the issue of sexual abuse and people with developmental disabilities. The author links prevention of abuse with promotion of appropriate sexual expression, and adds many ideas of "what you can do." He states that, "The punishment of appropriate sexual expression is as abusive as any other form of assault." He also discusses the "prison of protection" we have constructed around people with disabilities: protection from sexual information, protection from decision making, protection from relationships, and protection from society. The book discusses signs of abuse and how to recognize them. Finally, it concludes with discussion of ways to promote a "ring of safety" for people, including: understanding of personal rights, healthy self-concept and self-confidence, options for healthy sexuality, sex education, privacy awareness, ability to noncomply, and someone who listens.

TITLE: Harm's way: The many faces of violence and abuse against persons with disabilities

AUTHOR: The G. Allan Roeher Institute

PUBLICATION INFORMATION: 1995

The G. Allan Roeher Institute
Kinsmen Building, York University
4700 Keele Street
North York, Ontario M3J 1P3
CANADA

This study focused on violent or abusive circumstances experienced by people with disabilities and the impact of this on their lives. These circumstances include physical, sexual, emotional, and verbal abuse; denial of rights, necessities, privileges, and opportunities; and failure to respond to complaints of abuse and violence. The information for this study came from a Canadian survey of people with disabilities, and from interviews and focus groups with service providers, police, advocates, and family members. Also included as sources of information are a review of the literature on this topic and Canadian case law and statutes.

The author identifies factors which can contribute to such abuse, such as negative social stereotypes concerning disability and having caregivers who may lack adequate support and training. Also considered are issues of disclosure and identification of violence and abuse as well as responses (legal and otherwise) to the problem after it has been disclosed. Recommendations are offered for policy, program reform, statutory reform, providing information to concerned parties about the issue, and increased support from communities.

TITLE: Vulnerable: Sexual abuse and people with an intellectual handicap

AUTHOR: Senn, C. Y.

PUBLICATION INFORMATION: 1988

The G. Allan Roeher Institute
Kinsmen Building, York University Campus
4700 Keele Street
Downsview, Ontario M3J 1P3
CANADA

The author of this book claims that while sexual abuse has become a major issue in recent years, the sexual abuse of people with an intellectual handicap (i.e., mental retardation) has been virtually ignored in the public discussion and policy-making around the issue.

The author explores the myths surrounding sexual abuse and the myths surrounding people with mental retardation. The book focuses both on children and adults and the author shows how the myths surrounding disability contribute to the vulnerability of people with disabilities. This vulnerability seems to be well recognized, yet the author reports that it is almost impossible to get accurate measures of either prevalence or incidence of sexual abuse. Through a review of the literature which contributes to the understanding of sexual abuse of individuals with mental retardation the author suggests: (1) when sexual abuse is reported, 99% of the victims are assaulted by people known to them, (2) only 20% of assaults are reported, and (3) depending on the sampling and information gathering techniques used, estimates range from 25% to 83% of women and up to 32% of men with mental retardation have experienced sexual abuse. The author concludes that children with disabilities are at higher risk for sexual abuse than other children and adolescents, and that girls and women with disabilities are the most likely victims.

The author describes ways people with mental retardation use to indicate that they have been sexually abused and explores treatment and prevention issues. The book also addresses issues such as inaccessibility of services for individuals with mental retardation, offenders who have mental retardation, and legal issues in sexual abuse of children. The book concludes with recommendations to protect individuals with mental retardation from sexual abuse.

TITLE: Violence and abuse in the lives of people with disabilities: The end of silent acceptance?

AUTHOR: Sobsey, D.

PUBLICATION INFORMATION: 1994

Baltimore: Paul H. Brookes Publishing Co.

Sobsey's book is a comprehensive study of the issue of disability, violence, and abuse. Once a registered nurse in a facility for people labeled developmentally disabled, Sobsey begins his book with his own personal reflections on the incidence of abuse. Combining this personal narrative with research and a literature review makes this work a valuable resource.

The book is divided into two sections. The first Understanding Abuse, covers research and conceptual models of abuse. He reviews almost 30 studies which examine the relationships between abuse and disability, and also supplies data on characteristics of victims and offenders of sexual abuse (i.e., age, gender, disability level, situation of

the victim; and age, gender, and means of access of the offender). Also included in this section is a chapter on caregiver abuse, which includes euthanasia, sterilization, institutionalization, slavery, and the use of drugs as a means of control. The last chapter in this section critiques the major models used to explain abuse.

The second section of the book, Preventing abuse, takes a multimodel approach to prevention. Suggestions on interventions include the individual, the caregivers, the environment, law enforcement, and society at large. These suggestions are practical and useful, and also helpful is the Appendix which includes names and address of people and agencies working in this field who can link interested people with valuable resources.

TITLE: Sexuality, disability and abuse: An annotated bibliography

AUTHORS: Sobsey, D., Gray, S., Wells, D., Pyper, D., & Reimer-Heck, B.

PUBLICATION INFORMATION: 1990

University of Alberta
Severe Disabilities Program
6-102 Education North
Edmonton, AB T6G 2G5
CANADA

This annotated bibliography lists literature from a wide range of disciplines and perspectives relevant to sexual assault and abuse of people with disabilities. It is an attempt to provide a comprehensive review of the literature in this area and lists research studies, position papers, program descriptions, clinical reports, and media accounts. This should be an excellent resource for anyone interested in sexual assault and abuse of people with disabilities.

MULTICULTURALISM AND DIVERSITY

This section includes materials related to specific ethnic and/or cultural groups, as well as materials which more broadly address issues of diversity of multiculturalism. As there is a rapidly expanding amount of literature in this area, this bibliography only contains a sampling of that information.

TITLE: Multicultural education: Issues and perspectives

AUTHORS: Banks, J., & McGee Banks, C. A. (Eds.)

PUBLICATION INFORMATION: 1989

Allyn and Bacon
160 Gould Street
Needham Heights, MA 02194-2310

"A key goal of multicultural education is to change schools so that all students have an equal chance to achieve." Despite increasing cultural diversity in our classrooms, sensitivity to this diversity is not generally present in our educational system. This book is intended for pre-service teachers as an overview of comprehensive multicultural education and focuses specifically on developing a sensitivity in the classroom to ethnic, gender, and disability variation in students. Chapters include: the concept and history of multicultural education, social class and religion, gender, ethnicity and language, exceptionality, and school reform--including parental involvement.

TITLE: Double discrimination: Issues and services for people with learning difficulties from black and ethnic minority communities

AUTHORS: Baxter, C., Poonia, K., Ward, L., & Nadirshaw, Z.

PUBLICATION INFORMATION: 1990

King's Fund Central & the Commission for Racial Equality
Bailey Distribution Ltd., Dept. KFP
Learoyd Road, Mountfield Industrial Estate
New Romney, Kent TN28 8XU
ENGLAND

We live in a multicultural society and yet most of the key literature on developing services for people with learning difficulties has ignored this fact. Most national, regional and local plans for service development in this area show a similarly "colour blind" approach. The particular experiences, circumstances and needs of black and ethnic minority children and adults with learning difficulties and their families are ignored, or assumed (often incorrectly) to be the same as those of their white peers. While the authors make it clear this handbook is not a blueprint for the creation of antiracist services, it is intended to help service providers in infant, pre-school, school, adult, and older person's services for persons with learning difficulties and their families work toward more antiracist services. Included are stories from parents and persons with disabilities, cartoons, and photographs that are both thoughtful, sensitive, and celebratory of persons with learning difficulties of minority backgrounds.

TITLE: A bibliography of selected resources on cultural diversity: For parents and professionals working with young children who have, or are at risk for, disabilities

AUTHOR: Edmunds, P. T.

PUBLICATION INFORMATION:

PACER Center
4826 Chicago Avenue S.
Minneapolis, MN 55417-1055

This is a bibliography of resources on cultural diversity. The first section is more general information including printed and audiovisual materials as well as some organizations. The second section offers information on selected cultural/ethnic populations (specifically, Asian/Pacific Islander, African American, Hispanic and American Indian).

TITLE: Demographics and cultural diversity in the 1990s: Implications for services to young children with special needs

AUTHORS: Edmunds, P., Martinson, S. A., & Goldberg, P. F.

PUBLICATION INFORMATION: 1990

PACER Center
4826 Chicago Avenue S.
Minneapolis, MN 55417

This 10-page booklet offers a current look at the changing demographics across this country of children of color who are at risk for disabilities. It begins with a look at why we need to talk about multiculturalism and goes on to discuss the impact of poverty on people of color relating specifically to preschool age children. The booklet provides brief interviews with several people working in the field who are attempting to make their systems more responsive to multiculturalism. It also provides further resources on the areas discussed.

TITLE: IMPACT: Feature issue on supporting diversity

AUTHORS: Horton, B., McBridge, M., & Shoultz, B. (Eds.)

PUBLICATION INFORMATION: 1996

Minneapolis: Institute on Community Integration, University of Minnesota.

The focus of this issue of IMPACT is on services for persons with developmental disabilities that support the whole person by acknowledging, respecting, and incorporating aspects of identity such as race, ethnicity, religion, sexual orientation, gender, age, and class. This issue is about learning from people how to best serve them, rather than making assumptions about what they need or expecting them to fit into a certain system or model. It is about asking tough questions regarding the best ways to meet the needs of culturally diverse persons with developmental disabilities and their families, and being willing to hear a variety of answers, some of which are critical of the ways things are currently done. It is about the role of cultural communities in meeting the needs of persons with disabilities. And it is about the successes being experienced in innovative programs across the country.

TITLE: Disability and culture

AUTHORS: Ingstad, B., & Whyte, S. R. (Eds.)

PUBLICATION INFORMATION: 1995

Berkeley: University of California Press.

Traditionally, the concept of disability has been studied from a medical or sociological perspective. Consequently, few examinations of the effects of culture on our understanding of disability have taken place. Disability and culture is an edited collection of essays on the relationship between disability and culture. Essays are based, for the most part, on participant-observation or interview studies in a large

variety of countries, such as, Borneo, Turkey, Sweden, and Nicaragua. Insightful and careful observations and analysis by the authors help the reader both to reframe disability in terms of social processes and from a global, multicultural perspective and to explore the significance of disability in light of fundamental, culturally determined assumptions about humanity and personhood.

TITLE: American Indian cultural perspectives on disability

AUTHORS: Joe, J. R., & Miller, D.

PUBLICATION INFORMATION: 1987

Native American Research and Training Center
University of Arizona
1642 East Helen
Tucson, AZ 85719

This monograph offers insight into the cultural dimension of disability specifically related to the American Indians. It looks at some common perceptions of disability and discusses the Indian and non-Indian traditions and approaches regarding attitudes toward disability, examining differences and broader cultural values. It also offers specific examples of where cultural differences and misunderstandings have arisen when the Indian becomes a client in the non-Indian service world as well as recommendations to providing better understanding and services. Also discussed is the bi-cultural nature of Indian culture today and a brief historical insight as to how this occurred.

TITLE: Developing cross-cultural competence: A guide for working with young children and their families

AUTHORS: Lynch, E. W., & Hanson, M. J.

PUBLICATION INFORMATION: 1992

Baltimore: Paul H. Brookes Publishing Co.

This book first discusses issues of ethnic, cultural, and language diversity, providing insight into concepts of cultural identity and cultural considerations for interventionists which include self-awareness, awareness and understanding, as well as developing communication. All of these areas contribute to working toward what they

call a culturally competent system. The book then looks at families from a variety of cultural backgrounds including African, Asian, Native, European, Latino, Native Hawaiian, Middle Eastern and Filipino.

TITLE: Ethnic families in America (3rd ed.)

AUTHORS: Mindel, C. H., Habenstein, R. W., & Wright, R., Jr. (Eds.)

PUBLICATION INFORMATION: 1988

Elsevier Science Publishing Co., Inc.
52 Vanderbilt Avenue
New York, NY 10017

The growing interest in ensuring that services are responsive to the culturally and ethnically diverse groups that make up most communities has produced books and articles that attempt to increase understanding. The most difficult issue such attempts face is that of avoiding further stereotyping of specific groups. This book contains chapters on European (Polish American, Catholic Irish American, Greek American, Italian American), Hispanic (Mexican American, Cuban American, Puerto Rican American), Asian (Korean American, Chinese American, Japanese American, Vietnamese American), historically subjugated (Black American, Native American), and socioreligious (Amish, Jewish American, Arab American, and Mormon) "ethnic" minority families. A good reference source, this book sometimes falls into the trap of perpetuating stereotypes but at other times offers valuable information. For information on any one minority group, this book should be read along with other references (given at end of each chapter) rather than as a sole information source. For insights on the importance of recognizing and affirming diversity, the book provides a valuable overview.

TITLE: "I'm not Indian anymore": The challenge of providing culturally sensitive services to American Indians

AUTHOR: O'Connor, S.

PUBLICATION INFORMATION: 1993

In J. A. Racino, P. Walker, S. O'Connor, & S. J. Taylor (Eds.), Housing, support, and community: Choices and strategies for adults with disabilities (pp. 313-331). Baltimore: Paul H. Brookes Publishing Co.

This chapter describes services provided to the Lakota at the Pine Ridge Reservation in South Dakota through Southern Hills Developmental Services. Issues of culture and service provision are discussed, including ways of providing services on the reservation so people are not forced to move away to find the services they need. Traditionally, the service system has disregarded people's cultural identity. As an alternative, this chapter highlights the ways in which Southern Hills Developmental Services attempts to respect and support people's culture.

TITLE: Multiculturalism and disability: A collection of resources

AUTHOR: O'Connor, S.

PUBLICATION INFORMATION: 1993

Syracuse, NY: Center on Human Policy, Syracuse University.

Part I of this resource packet is an attempt to place disability within the larger context of multiculturalism. By placing disability within this context, the article explores issues of discrimination that have faced many people because of race, gender, ethnicity, class, age, and disability, to name a few, and the similarities that exist with such experiences. Part II offers annotations of books, articles, materials, and organizations that are dealing with issues of multiculturalism and disability as well as some that deal more specifically with issues such as poverty or ethnicity.

TITLE: Issues in culturally competent services delivery: An annotated bibliography

AUTHORS: Rider, M. E., & Mason, J. L.

PUBLICATION INFORMATION: 1990

Research and Training Center on Family Support
and Children's Mental Health
Portland State University
P.O. Box 751
Portland, OR 97207-0751

This annotated bibliography was developed as part of the Minority Cultural Initiative Project to help explore the issue of culturally competent service delivery to children and youth with emotional disabilities and their families. The review was limited to contemporary perspectives spanning the last three decades and covering communities or groups of color within the United States. It is an attempt to present

theoretical perspectives regarding culturally appropriate service delivery and to show practical applications of theory and research. The document is divided into five sections--one that addresses multicultural issues and four that address culturally specific issues.

TITLE: Intellectual disabilities in the Nordic welfare states

AUTHORS: Tossebro, J., Gustavsson, A., & Dyrrendahl, G (Eds.)

PUBLICATION INFORMATION: 1996

Hoyskole Forlaget
Norwegian Academic Press
Postboks 2170 Posebeyen
Dronningensgt
N-4602 Kristiansand S.
NORWAY

In the last ten years the Nordic countries have undergone extensive change in the policies toward people with disabilities. During this time, consequently, the everyday lives of these people have also changed. Written for both international and Nordic audiences, Intellectual disabilities in the Nordic welfare states analyzes the services available and changes in this to people with labels of intellectual disabilities within the Nordic welfare states--Norway, Sweden, Denmark, Finland, and Iceland.

TITLE: Community living: A multicultural perspective

AUTHORS: Traustadottir, R., Lutfiyya, Z. M., & Shoultz, B.

PUBLICATION INFORMATION: 1994

In M. F. Hayden & B. H. Abery (Eds.), Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities (pp. 405-426). Baltimore: Paul H. Brookes Publishing Co.

This chapter explores multiculturalism as it applies to the field of developmental disabilities. The first section introduces the concept of multiculturalism. Subsequent sections examine how gender, class, and race influence people with disabilities and the services they receive. These dimensions form a starting point for unraveling and mapping out the complex issues that influence service delivery to persons with

disabilities, as well as for directing policymakers and service providers in a direction that does not require individuals to conform to the customs and assumptions of the dominant culture.

TITLE: Disability and diversity: New leadership for a new era

AUTHORS: Walker, S., Turner, K. A., Haile-Michael, M., Vincent, A., & Miles, M. D.

PUBLICATION INFORMATION: 1995

President's Committee on Employment of People with Disabilities
Howard University
Research and Training Center for Access to
Rehabilitation and Economic Opportunity
2900 Van Ness Street, N.W.
Holy Cross Hall, Suite 100
Washington, DC 20008

"Minority persons with disabilities are important in the struggle for the full equality and empowerment of people with disabilities. Minority persons with disabilities must be able to develop and exemplify leadership and advocacy skills." Yet, despite statements such as this a person with a disability and who also comes from a minority background continues to suffer a double discrimination in society. Disability and diversity: New leadership for a new era is an examination by advocates, policy makers, government department representatives, and university researchers of the combined handicaps of what it is to have a disability and to be of a minority background in America. Topics examined include: policy and practice--from then to now, rehabilitation and diversity--both in counseling clients and in training counselors, provision of school and adult services in manners that take into account cultural diversity, and strategies for empowerment for persons with disabilities of minority backgrounds.

DISABILITY STUDIES

The studies featured in this section of the bibliography focus on mental retardation as a social and cultural construct. Such an approach fits into the broader field of Disability Studies. Consistent with a Disability Studies perspective, the perspectives and experiences of people labeled mentally retarded provide a starting point for this literature.

TITLE: Freak show: Presenting human oddities for amusement and profit

AUTHOR: Bogdan, R.

PUBLICATION INFORMATION: 1988

Chicago: The University of Chicago Press.

The societal presentation of different appearances as things to be feared is not a new phenomenon. Rather, persons with differences or disabilities--the freaks of Bogdan's freak shows--have long been objects of attraction, fear, and amusement. Using qualitative research methods to carry out an in-depth, historical study of freak shows and their participants, managers, and promoters, Bogdan proposes an interesting theory on "freaks." He tells us that, "our reactions to freaks are not a function of some deep-seated fear or some 'energy' that they give off. Rather, our reaction is a result of our socialization, and the way our social institutions managed these people's identities... 'Freak' is not a quality that belongs to the person on display. It is something that we created: a perspective, a set of practices--a social construction."

TITLE: The social meaning of mental retardation: Two life stories

AUTHORS: Bogdan, R., & Taylor, S. J.

PUBLICATION INFORMATION: 1994

New York: Teachers College Press.

Based on in-depth interviews with two individuals with labels of mental retardation--one woman and one man, who were both former inmates of institutions, the authors look at how these two persons see themselves. Using the life stories of these two people Bogdan and Taylor challenge the concept of mental retardation. The authors argue that mental retardation is not a real entity, but rather a social construct.

TITLE: Interpreting disability: A qualitative reader

AUTHORS: Ferguson, P. M., Ferguson, D. L., & Taylor, S. J. (Eds.)

PUBLICATION INFORMATION: 1992

New York: Teachers College Press.

This book is a compilation of qualitative and interpretive studies of people with disabilities or their families. The chapters are divided into four parts: disability at the edges of life, disability and the schools, disability and the community, and disability and culture. Specific stories include: communication on the neonatal unit, the social construction of child abuse, lack of help for elderly people with disabilities; autistic students on one high school, "the town fool," and the experience of disability and the dilemma of normalization. The book ends with a discussion of the future of interpretive studies in disability studies.

TITLE: The politics of caring

AUTHOR: Foster, S. B.

PUBLICATION INFORMATION: 1997

The Falmer Press
Taylor & Francis Inc.
242 Cherry Street
Philadelphia, PA 19106-1906

Foster studied 13 admissions to the Weston Center, an institution for people labeled developmentally disabled. She also studied four people whose applications for admissions were denied. She offers discussions on institutionalization and deinstitutionalization, the limits and powers of professionals, and private troubles such as family involvement or lack of involvement.

TITLE: A world without words: The social construction of children born deaf and blind

AUTHOR: Goode, D.

PUBLICATION INFORMATION: 1994

Philadelphia: Temple University Press.

"Chris was providing her otherwise impoverished perceptual field with a richness her eyes and ears could not give her. She accomplished this by the use of her available and intact bodily resources -- her good eye, her nose, her muscles, and her skeletal frame. I as, and still am, struck by the inventiveness in this activity." This book is the result of Goode's participant-observation study of two children, one of whom is Chris, with congenital deaf-blindness and mental retardation. Based on countless hours of studying, teaching, observing, and playing with these two children--one of whom lived in an institution and the other in her family home, Goode helps the reader to see that humans both with and without formal language can indeed communicate with those around them in many ways. He suggests that it is impractical to interpret these children's behaviors using ideas about normal behavior of the hearing and seeing world.

TITLE: Culture and retardation: Life histories of mildly mentally retarded persons in American society

AUTHORS: Langness, L. L., & Levine, H. G. (Eds.)

PUBLICATION INFORMATION: 1986

Boston: D. F. Reidel Publishing.

This compilation of ethnographic articles focus on the life experiences of people labeled mildly mentally retarded. They stress that mental retardation is more of a sociocultural phenomenon than a medical/physiological one. The articles cover the subjects' lives in terms of their childhood, patterns of adapting to everyday life, and their response to the label of retardation. In addition, the editors offer a discussion about life history research of people labeled mentally retarded, as well as a discussion about anthropological contributions to this type of study.

TITLE: Perspectives on disability

AUTHOR: Nagler, M. (Ed.)

PUBLICATION INFORMATION: 1990

Health Markets Research
851 Moana Court
Palo Alto, CA 94306

In the introduction, the editor states, "The purpose of this text is to identify the significant and paramount concerns of the disabled community and to illuminate the obstacles which are often imposed on this minority. Further, it is the intention of this book to remedy the lack of comprehensive information about the disabled and to present some of the conflicting perspectives which surround many disabled issues." The book is divided into 10 section with chapters presenting the perspectives of people with and without disabilities. The section include: what it means to be disabled, societal attitudes about disability, social encounters, family experiences, sexuality and disability, educational opportunities and barriers, employment and disabled workers, legal issues, medical concerns, and what it means to be different: perspectives of the disabled. An appendix contains a bibliography of American and Canadian disability organizations.

TITLE: The variety of community experience: Qualitative studies of family and community life

AUTHORS: Taylor, S. J., Bogdan, R., & Lutfiyya, Z. M. (Eds.)

PUBLICATION INFORMATION: 1995

Baltimore: Paul H. Brookes Publishing Co.

This book looks at life in the community from a unique perspective. It contains studies which look at community participation from the vantage point of people with developmental disabilities, their families, and the community. This purpose of the book is not to describe or promote specific support strategies, practices, or other good ideas, but to explore how life in the community is experienced directly by those with developmental disabilities and their families, whether or not they are involved in the human services systems.

The studies reported in this book address one or more of three major themes including: family life, the nature of community (whether defined in terms of associations and groups or geographically), and the nature of human services. This book contributes to general understandings but also provides useful insights and lessons to policy makers. People with developmental disabilities, family members, professionals, advocates, and others interested in life in the community.

ORDERING INFORMATION

To Order Resources in This Bibliography

The Center on Human Policy either directly or through Human Policy Press makes available resources and reports produced by Center staff and associates, but cannot sell books, reprints of articles, or documents produced elsewhere. Therefore, we are including here two lists—one of publishing companies (including toll-free numbers for companies that have them) and one of other selected resources for information about community integration. We suggest calling these companies and resources for cost information and publication lists.

Addresses and Phone Numbers of Publishers

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fax 615-749-6172

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http://www.allen-unwin.com.au/

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P.O. Box 10695
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50336-0695
1-800-666-9433
FAX: (515) 284-2607
simon@neodata.com
http://www.abacon.com/

Basic Books
HarperCollins Publishers
10 East 53rd Street
New York, NY 10022
1-800-386-5656 (for review/desk copies)
(303) 444-3541 (for orders)
fax (303) 449-3356
http://www.hcacademic.com/basic.htm

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http://www.hup.harvard.edu/

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212-654-8000

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5615 Fishers Lane
Rockville, MD 20852
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SELECTED NATIONAL RESOURCES FOR INFORMATION ABOUT COMMUNITY INTEGRATION

American Association on Mental Retardation (AAMR)
444 North Capitol Street, N.W., Suite 846
Washington, DC 20001-1512
202-387-1468 or 1-800-424-3688
fax 202-387-2193
aamr@access.digex.net
http://www.aamr.org

Beach Center on Families and Disability
University of Kansas
3111 Haworth
Lawrence, KS 66045
voice/tdd 913-864-7600
fax 913-864-7605
beach@dole.lsi.ukans.edu
http://www.lsi.ukans.edu/beach/beachhp.htm

Institute on Community Integration
University of Minnesota
102 Pattee Hall, 150 Pillsbury Drive, S.E.
Minneapolis, MN 55455
612-624-6300
fax 612-624-9344
ici@mail.ici.coled.umn.edu
http://www.ici.coled.umn.edu/ici/

Institute on Disability
University Affiliated Program
University of New Hampshire
7 Leavitt Lane, Suite 101
Durham, NH 03824-3522
voice/tdd 603- 862-4320
fax 603-862-0555
Institute.Disability@unh.edu
http://iod.unh.edu

The Council for Exceptional Children
1920 Association Drive
Reston, VA 20191-1589
voice 703-620-3660
tty 703-264-9446
fax 703-264-9494
http://www.cec.sped.org/

Federation for Children with Special Needs
95 Berkeley Street, Suite 104
Boston, MA 02116
1-800-331-0688 (in Massachusetts only)
voice/tty 617-482-2915
fax 617-695-2939
fcsninfo@fcsn.org
http://www.fscn.org/home.htm

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tty 312-413-0453
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